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VALUES OF LAY AND PROFESSIONAL CARE: AN INTERPRETIVE ENQUIRY

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ABSTRACT

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Values of care are dynamic and complex which prompted this enquiry to seek answers to 'What are the lay and professional values of care in the context of motor neurone disease and is there a difference between them which affects care delivery and receipt?'. Motor neurone disease is a devastating terminal condition with no cure. Care is then the only option, which sharpens the need for its examination and clarification.

This report presents a phenomenological hermeneutic study which investigates lay and professional values of care, situated in the world of six people with motor neurone disease, six lay carers and a team of nine professional carers. The interpretive enquiry enables their lived experiences to be voiced, heard and recorded. Application of Heidegger's phenomenology and Gadamer's hermeneutics supports a clear decision trail of the interpretive-analytical process. Illustrations of receipt and delivery of care are presented through interpreted narratives from the participants, together with insight into the researcher's prejudices.

The study discovers three ways of caring, with most alignment between the two lay groups. The professional carer stance is predominantly functional and illustrates detachment from the experience of living with illness whereas the recipients' needs are holistic. These two value structures, the mechanistic and the hermeneutic are in tension. To redress this imbalance, support for a dispositional shift in professional values is advocated. Education is a key component for this change and four groups of supportive professional learning recommendations are proposed. These are located in the domains of the philosophical/ontological, relational, ethical and trajectory of disease to influence professional curricula for greater alignment with client need.

MOTOR NEURONE DISEASE

Motor neurone disease (MND) is characterised by degeneration of motor neurones in the brain and spinal cord leading to progressive weakness and wasting of the muscles they serve. The onset is usually insidious, the first symptom often being a weakness in one limb, usually the hands or feet. Bulbar involvement affects speech and swallowing, impaired control of emotional responses and the possibility of choking or pneumonia (Evans and Lewis, 1989). The incidence of MND is 1 in 50,000 which is similar to multiple sclerosis, the prognosis is typically 3 months to 3 years although there are exceptions of life extending over 15 years.

MND is progressively debilitating and deprives its victims of movement, breath and eventually life. The person who develops MND will experience no remissions, and there are no known causes and no known cure. After diagnosis, death is certain but its timing is not. Loss of muscle power escalates but the pattern and selectivity of the loss in uncertain. The need for holistic care becomes increasingly evident but the values steering such need or underpinning its delivery are unclear.

There is increasing medical research attempting to find causes and cures of motor neurone disease. The most recent pharmacological advance being a drug called Riluzole. The hope which medical research brings is vital to people with MND and their loved ones. However, currently a cure seems remote even though the drug treatment may extend life for up to 3 months but this currently creates a situation which demands more care.

Sebring and Moglia (1987) identify that much of the literature on terminal or paralysing illnesses only partially describes the experiences of people who develop motor neurone disease. MND is so devastating that appreciation of peoples' experiences relating specifically to this disease can help us in our understanding, future care provision and educational preparation. An understanding of their world can also offer insights into the worlds of other severely disabled people and their carers.

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CHAPTER 1: INTRODUCTION

1.1. Introduction

This research study focuses on the experiences and values of caring as disclosed by people in the world of motor neurone disease. The cared for, their lay carers and their professional carers all tell stories of their experiences in this world in relation to care received or given. The hermeneutic phenomenological investigation into these caring worlds offers empirical insights to progress the knowledge base of caring in the context of neurological disability, to illuminate similarities and differences between the participants' values of caring and to generate professional carer learning recommendations for the promotion of client centred care delivery.

Care is a complex concept which is why it is important to focus a study on this phenomenon. Care can be an umbrella term to reflect measurable health and social gain outcomes or be considered as a personal disposition and way of being. Both perspectives are value driven. However, there is a lack of attention for understanding caring values, particularly value differences between those who require care and those who offer care. Locating care within a health setting finds it secondary to the importance of cure. In the current ideology of outcomes, performance indicators and league tables, it is possible for care to be taken for granted or even ignored. Underlying values and practices of care require clarification to promote their presence and contribution to care delivery. In the context of motor neurone disease, cure is not an option, which is true amongst many chronic neurological and non-neurological diseases. Care, with its diverse value base, then becomes the remaining option that sharpens the need for its examination, clarification and appreciation from the different perspectives of people involved.

1.1.1. Strengths of the research study

Apart from the importance of the topic area, the study contributes four major achievements. First, successful engagement with the methodological challenges of interviewing and gaining evidence from people in extreme situations, that is the cared for who are dying of an incurable, debilitating disease and their partners. Second, the strength of the rigour attained with a clear analysis decision trail. This can be a neglected feature of qualitative research.

Third, the individual group findings that offer insight into three ways of caring, learning and being in the context of motor neurone disease. Fourth, the learning recommendations for professional carers that emanate from the evidence of the three participant groups.

1.1.2. Situating the study

Offering the researcher's rationale for the choice of research topic offers insight into the stance and situatedness of the researcher which in turn assists the reader to appreciate the interpretive turn. This requirement necessitates illumination of the history and 'prejudices' of the researcher, which is the justification for this section where I, as the researcher, offer my 'story'.

My motivation for training as a nurse in the late 1970s arose from a commitment and responsibility to care for others. Family life had thrown me into a caring role and I chose to learn how to be more effective in caring. The opportunity to understand caring and suffering and to make a positive difference to people's lives was the goal. In health care I soon realised the important contribution of the life sciences and the practical interventions for patient care. However, I did not experience an education that supported development in the affective and personal domains.

Incidents in practice did affect my understanding. A young army officer, hospitalised for a malignant melanoma, spoke to me after observing me interact with an elderly man dying of throat cancer. I was rather frightened of the elderly man as he was very fragile, emaciated and in some degree of pain. His cancer was external, it smelt and was unsightly which I found challenging to approach. He told me he was uncomfortable in the bed, as he was sitting up and his bony prominences were becoming sore. I decided to place a sheepskin rug under him and change his position at the same time but in so doing I had to be very careful not to hurt or distress him anymore, so I handled his frail body gently and slowly. I could feel his bones creak as I moved him. I was almost cradling him in the process, quietly informing him of my movements, conscious that he was quietly suffering and very withdrawn. Afterwards the army officer spontaneously said to me, 'You really care for that man, nurse. I could see it in how you softly spoke with him, moved him, and offered him your contact'. This statement really took me by surprise as I did not realise I was being observed. However, it gave me a sense of achievement, learning, gratitude and puzzlement.

The achievement was fuelled by my obvious success in his eyes concerning my intervention, the learning was how important it was to combine practicalities with ways of being, the gratitude was the extrinsic feedback from the interaction and the puzzlement was what motivated his remark to me? Why had another patient remarked about an observed caring behaviour? My conclusion was he knew he was also without cure, was also dying and was a little comforted to appreciate that he may receive 'care'.

One Sunday afternoon four years later, whilst on duty as a staff nurse in a regional neurological unit, a woman was admitted for a nutritional assessment. She had a diagnosis of motor neurone disease and arrived on the ward in a wheelchair, accompanied by her two daughters. She appeared an old withered figure, crouched, thin, dribbling. She was immobile, unable to talk, eat or drink or even swallow her own saliva. Her daughters had been attending her at home for eight months but were anxious about her increasing weight loss.

As I admitted Mrs F, with the assistance of her two daughters, I felt in the middle of absolute engrossed care. Similar to the army officer I was deeply moved by the caring interactions I witnessed. The daughters were practically adept, gentle and compassionate. They cracked jokes amongst the three of them and were laughing as they sorted out her clothes and helped her to settle into her hospital bed. They mopped up her dribbling instantly and respectfully, they scratched her nose for her, they took her to the toilet, they hugged and loved her. I thought they were caring experts guided by love and knowing.

Their ways of being affected me. I had witnessed absolute compatibility between carer and cared for. I considered relationships between clients and professional carers and considered their strengths and deficits. Questions arose of, 'How can professional carers lay claim to be the legitimate carers when this level of expertise in practical and interactional care exists in the lay community?', ' How, and what, can we as care professionals learn from them?', 'How can ways of caring be more positively promoted and supported in professional carers to match the needs and value base of those requiring such care?' Reflecting on my stance and prejudice allowed me to appreciate the need for educational opportunities to support professionals in this pursuit for improved client care.

These two separate but related incidents concerning the nature and being of caring are two of many from my clinical experience.

My questions demanded responses which led me into wanting to know more about caring values of people who give and receive care, their motivations, external influences and ways of promoting such practices.

1.2. AIM AND PURPOSE OF THE STUDY

My questions about being in care became particularly focused in the world of motor neurone disease (MND). To me, MND is one of the most horrific physical conditions that anyone could experience. Through examining care and caring in this context I felt it would be investigating care at the edge of human endurance, illuminate the being of care at its most critical and offer insights of value to care professionals, the cared for and lay carers. To progress this goal, three questions were framed;

i) What is the experience of living in the world of motor neurone disease?
ii) What does care mean to people with MND, their lay carers and their professional carers in the context of motor neurone disease?
iii) Can a greater understanding of lay and professional caring values influence care practices?

These three questions evolved into the central research question of 'What are the lay and professional values of care in the context of motor neurone disease and is there a difference between them which affects care delivery and receipt?'

The purpose of this study is to influence professional care education and practice for the benefit of clients, through gaining a greater understanding of the meaning and values of care and caring, as lived and experienced by lay and professional people in the world of motor neurone disease.

1.3. RESEARCH APPROACH

When seeking a greater understanding of meanings and values of a phenomenon, application of the principles of phenomenology and hermeneutics are congruent to developing an empirical study. Heidegger's phenomenology offers an interpretive enquiry focus into 'being-in-the-world'. He drew on hermeneutics as his approach for questioning and analysing such being.

He held the premise that interpretation is universal for all understanding; presupposes prior understanding and that it is only possible to interpret according to one's own lived experiences. The term hermeneutic is reported to have been used since the eighteenth century to refer to the interpretation of texts (Outhwaite 1987) but it has since been further developed by many scholars. Hans-Georg Gadamer (1900-) is a notable contributor and his metaphors of prejudice, hermeneutic circle, fusion of horizons and historicity are helpful in this regard.

Heidegger used the concept of forestructure (prejudice) to explain that one's past experiences and beliefs cannot be denied in interpretation. Walters (1995) suggests that to accommodate this feature in research it is necessary for the researcher to continually reflect on their involvement and possible changing perspective during a study. Therefore the researcher maintained a reflective journal and parts of this report are written in the first person. This approach is supported by Webb (1992:747) who argues that it is ‘acceptable to write in the first person when giving a personal opinion or when one has played a crucial role in shaping the data or ideas presented’.

Data collection was secured through two guided conversations with three groups of participants from the world of motor neurone disease: people with MND, their lay carers and their professional carers. A five stage analysis process was specifically developed, initially drawing on the work of Colaizzi (1978) and Van Manen (1990), which included participant verification of the developing interpretation.

1.4. OVERVIEW OF CHAPTERS

There are ten chapters in this report. The next chapter offers insights into perceptions and experiences of lay and professional care through considering layers of thinking about care; first from the autobiographies of three participant groups, second from knowledge foundations of philosophy and theology, third from the practical disciplines of psychology, education, sociology, ethics (including feminism), socio-biology and anthropology. The influences of these layers are then considered in relation to three care professions; nursing, medicine, and social work. The literature focusing on autobiographies of lay and professional carers was collected after analysis of the evidence in this study . Similarities arose between the autobiographical accounts and the evidence from this study and these are highlighted.

Further literature is not explicitly discussed with the findings as these are grounded in the evidence and robust in their own right.

Chapter 3 consists of four parts. First, the research question is considered in the light of research paradigms. The appropriateness of an inductive, interpretative approach is established and the features of phenomenology and hermeneutics are discussed in part two. Third, the process of analysis, congruent to the phenomenological hermeneutic tradition is charted and clarified. Fourthly, issues of establishing rigour in the research are discussed.

The iterative process of organising the study is reported in chapter 4 . The importance of being able to follow a decision trail is clearly linked to the pursuit of academic rigour. However, no trail is linear which creates difficulties in its presentation. As each decision affects another decision, the chapter winds its way through the evolving journey in five sections. First, particular attention is given to practical ethical considerations. Second the effects of the pilot investigation on the main study are discussed and third, how access was secured to the three sample groups of participants. Fourth, the sample in the study is introduced and fifth, the protocol for collection of evidence is explained.

The interpretative analysis trail from the guided conversations to the group models of care is presented in chapter 5. Three trails are constructed which reflect the three groups of participants. Each group is addressed separately to illustrate the analysis process with extracts from the original texts. Although the process of interpretive analysis identifies five stages, the first four stages of the analysis process are presented in this chapter with the subsequent three chapters addressing the final stage.

Presenting findings and conceptual models of a phenomenon in a hermeneutic study raises an interesting tension. If it is accepted that continuous dialectical, questioning interchange between text and interpreter is the vehicle for promoting fusion of horizons, then it follows that meaning is not a fixed entrenchment but is always open to interpretation. Presentation of findings therefore does not indicate a final end point but merely a stage in the conversation. Therefore, chapters 6, 7 and 8 present a stage in the conversation, offering the constructed group categories and the individual group conceptual models of caring from the three participant groups.

Chapter 9 responds to the research question by offering a sense of the alignment and lack of fit (matches and gaps) between the values of lay and professional carers which can affect care delivery and receipt. Bourdieu's (1980) theory of practice is drawn upon for explanatory support into the different stances in care revealed between the three participant groups. Professional carer learning recommendations are established to influence practice for the promotion of effective care in the context of MND and the conceptual model of lay and professional care is presented.

Four sections constitute chapter 10. The first considers implications of the professional learning recommendations with a brief discussion on selecting curriculum content, the contribution of the wider community and the guardianship of care for the future. The second section summarises the outcomes and achievements of the study. Critique of any study is a vital component for recognition of its limitations and these are addressed in the third section with the final section considering implications of the study in terms of further research.

CHAPTER 2: PERCEPTIONS AND EXPERIENCES OF CARE

2.1. INTRODUCTION

It is suggested that the basis of meanings are 'shaped by the values of the constructors', (Guba and Lincoln 1989:8) so the use of any term is context dependent. The 'constructors' of care in this study focuses on three groups in the world of motor neurone disease: the cared for, their lay carers and professional carers. However as values are the result of cumulative years of contemplation, which build on each other, an exploration of care requires consideration from a wider influential field. This chapter presents layers of thinking about care which are illustrated in table 1.

The purpose of a literature review is to highlight what is already known about the subject under scrutiny, but also to identify gaps in our understanding. The 'theoretical' literature reviewed offers many dimensions of caring. A gap located is a lack of consideration for experiential experiences of care. The autobiographical literature explicitly achieves this perspective. In the context of MND, only one study was located which shed light on a three-way approach to caring. Cox (1992) investigated care from the perspective of the cared for, lay carers and occupational therapists but from a service provision function.

Table 1. Literature approach to examining perceptions and experiences of care

Lived experiences	Perceptions from experiences in caring from the cared for, lay and professional carers
Knowledge foundations	Philosophical and Theological perceptions
Practice Knowledge Disciplines	Psychology, Education, Sociology, Ethics (including feminism), Socio-biology and Anthropology,
Influences on three care professions	Nursing, Medicine, and Social Work*

*(The three health professions are taken from Campbell's (1984) template).

The use of words through language to describe care is a paradox as we need words but they are almost an obstacle, as caring can additionally be conveyed through glances, touch and presence. Indeed care can be more easily seen and experienced than analytically described. However, the words care and caring are embodied in our everyday language although their meanings can be diverse. A dictionary definition (Chambers 1993:257) of the noun, care, offers a sense of its diversity, 'affliction; anxiety' whereas the verb section includes ' to be inclined; to mind'. Its adjective, caring, is reported as, 'compassionate; concerned professionally (as the caring professions)'. Given this range of meaning from affliction to anxiety to compassion, and its use in a range of situations from personal relations to commercial advertising, it is unsurprising how Montgomery (1993:9) goes so far as to suggests the word caring has been 'trivialised'. However, she argues that in the context of health care, 'caring cannot be trivialised'. Pluralistic perceptions are important when trying to illuminate an evolving concept.

Seedhouse (1991) suggests there are two languages of care, the technical and the non-technical, with the former more highly valued. Leininger (1986:6) highlights this division stating 'the economic value of observing, comforting, and remaining with clients is receiving considerably less attention and financial value compared with high technology in the medical services'. How has this division arisen and how is it being maintained? Language offers strong clues. Technical care aspects adopt Cartesian objective reality words and their associated meanings such as cure, efficiency, cost, outcome. Non-technical language involves phenomenological expressions of person-hood, compassion and moral obligation (Seedhouse 1991). A hierarchy has evolved through value construction which is transparent through language, although Seedhouse argues this should not be so. He suggests adopting a single language so the variations of types of caring can be equally valued and understood. As values are a pivotal focus of this study they need clarification.

2.1.1. Values

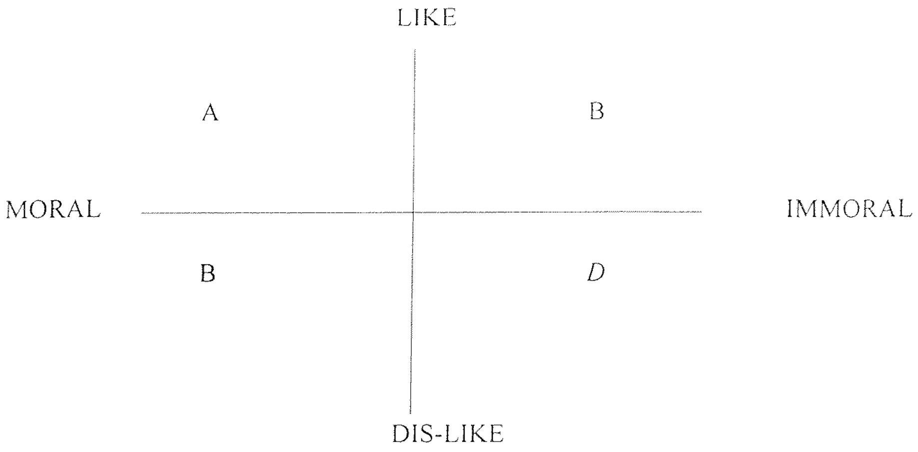
Values have complex origins, resulting from personal experience, education, culture, historical, political and psychological factors together with the influences of literature and the media. Although the question of values can present a maze of possibilities, Downie et al (1990) offer signposts by differentiating four types of values: social, personal, liking and moral.

Social values are influenced by culture, society and politics as well as institutions such as the family and work organisations. Personal values are influenced by social values but incrementally involve personal experiences. Liking values are seen as comparative in terms of one thing is liked in comparison to something else. Moral values are those which are 'held for their own sake and have an inter-personal quality' (Downie 1990:131). These two latter distinctions can be aligned to practical and philosophical values; the first being mainly concerned with objects and practical issues and the latter with states of Being and Being with others.

Downie and Telfer (1980) also speak of ideal values, which they suggest are similar to moral values. Values, whether ideal or moral can be seen as the corner stone of one's belief system. They are the base line that governs behaviour, opinion and judgement of others. However, values do have a sense of the dynamic, they can be swayed by context, priority of outcome and circumstance. A person may find themselves in a situation whereby circumstances make them chose to act against their ideal values. So although one's values may serve as a template for practice or action, in certain circumstances that template may be adjusted as values are actualised through everyday life. Ideal values may be rooted in kindness, goodness and service but if a doctor makes a diagnosis of MND, then the professional may experience a tension between beneficence and honesty. This may delay telling the patient their diagnosis, not because they are dishonest but because they wish to delay harm for the patient as long as possible and may judge that a few months of ignorance maybe the 'kinder' option.

Figure 1 offers an illustration of the possible relationship between liking and moral values. Examining four carers, *A* could be viewed as a person with positive moral values and who likes the cared for which could result in the most positive practice; *B* could be viewed as the carer having a moral foundation but not liking the cared for which may create some tension but the moral base should drive the care delivered; *C* could be viewed as liking the cared for but not having a strong moral value base to guide practice and therefore potentially lead to uncaring practices as described by Blustein (1991). *D* is the worst scenario for the cared for, when the carer has no moral foundation and also dislikes the cared for.

Figure 1. Dimensions of liking values and moral values



The distinction between liking and moral values offers a parallel between practical and philosophical aspects of care. A similar dimensional analysis could portray these two variables whereby the best scenario is excellence in practical skills and ways of being-in-care (person centred behaviour) with the worst scenario as poor skills and poor ways of being-in-care. Although these two distinctions can be made, being 'cared for' creates a demand for union of these two dimensions, although being a carer may promote their separation. The stance of the individual seems a determining factor for the underlying values and the practice of care.

Remaining with this practical and philosophical distinction, Blustein (1991) offers four uses of the word care which he labels as conceptual and philosophical distinctions. Blustein (1991:27-8) offers a useful framework to recognise the complexity of the concept and diversity of values which can underpin care and caring as follows:

Liking/Practical values

1. to care for: involving affection, liking, a personal aspect and public aspect of caring
2. to have care of: focusing on responsibility to manage, provide for, attend to the needs of another

Philosophical/moral/ideal values

3. to care about: having one's own welfare linked with that of the person one cares
4. to care that: in terms of a wider agenda to caring, knowing and caring that millions are starving

There are various combinations of these four approaches to caring. Blustein suggests that a love relationship and friends would favour the first two. Parents may involve all four, as a parent would care for their children, have care of them, care about them and care that they flourish (Blustein 1991). That permutations exist reveals the inclusion of other factors which he suggests are interest and commitment. Scott (1995) would probably favour points 2 and 4 as priorities and motivators of care professionals. He suggests professionals are taught theoretical and manual skills required for their professional role, such as how to wash a patient in bed, how to carry out a physical examination, what to observe for and how to lift a patient properly but suggests in there is still a lack of adequate conceptual understanding of the concept of care. He adds that this understanding may grow though experiential learning. If an adequate understanding of the concept of care was present it could have two distinct effects; first in promoting higher quality of care through a greater understanding and second, it would be easier to justify more time and resources for the psychological/philosophical sense of care. This is an area still interpreted as less tangible and measurable so with 'unseen' benefits.

The importance of developing our understanding of care can be highlighted through Blustein's (1991) reminder of how care can be defective and he offers six examples. The first two are when caring is not integrated to one's central (ideal) values; when one cares against one's will which can lead to a loss of self-respect, as in loving a person who we may think is unworthy. Secondly when lacking sound judgement about something you care about, this may lead to disillusionment. The other cases of defective caring are caring to the extent that you stifle the personality of the one cared for; caring too much so that preoccupation and obsession arise; paying too much attention to someone so one's duties and obligations are neglected which reduces the greater good for all; and finally caring about a cause so much that the interests of other human beings are ignored or neglected.

The importance of value identification is supported by Kitson (1993) as values influence and inform ways of thinking and help to identify conceptual boundaries. She locates how values are different to facts and concepts but how an investigation which seeks clarification of values can offer an interpretation and understanding of actions and thoughts that people may have about a certain phenomenon. Appreciation of the values of care and caring from different groups of people can therefore offer insight into conceptual boundaries which may exist. The starting point for this challenge is to consider the perceptions from experiences in care from the three participant groups.

2.3. PERCEPTIONS FROM EXPERIENCES IN CARING

Ontological experiences of being cared for can contribute to the beginnings of an epistemological understanding. This assumption is the basis of this study. Capturing experiences of being-in-caring can inform our knowledge base and hence influence care education and practice. The starting point for examining literature begins with hearing and trying to understand stories and accounts of people involved in caring; the cared for and the caring. Although these experiences are reported at the beginning of this study, the researcher did not engage with this literature until the analysis of the study participants evidence was complete. Caution needs to be exercised not to use literature in a prospective, directed sense. Morse (1994:27) identifies it is to 'gain maximal awareness and to recognise leads without being led' which is why the theoretical aspects were reviewed first. Having achieved the analysis in chapters 6-9, it was encouraging to discover resonance between the published 'autobiographical' experiences and those of the study participants.

2.3.1. The Cared For

Perception of illness affects caring needs. If an illness is curable as opposed to not then different futures beckon and reactions are different. An MND sufferer, Whitehurst, (1995:49) suggests MND is,

'a lot like going from 37 to being 90 in six months. Your mind is unaffected apart from the jealously and sheer frustration as you watch people walking and talking, and the ever creeping realisation that you can't stop your body going down the toilet'.

Another MND sufferer, Henke (1968:765) continues with this theme by highlighting the need for people to understand 'that a change from adult independence to complete dependence is most frustrating and will lead to emotional changes such as sudden floods of tears or almost hysterical laughter'. Henke highlights the importance of relational aspects with others. First how loving kindness and understanding helped him to remain a person . This was vital to his care as it enabled him to express his personality which relieved tension caused by the disease.

Second the importance of 'remaining a person', a key finding from the study's MND participants who in agreement with Henke, place second the 'caring for' aspects: receiving practical assistance from professional in terms of learning breathing exercises to reduce panic, hints on how to prepare food to be easier to swallow and body positioning to aid swallowing and comfort. These two central caring values immediately reflects the need for union of philosophical and practical values; the importance of being treated as a person within MND and receiving practical assistance to function with day to day aspects of living.

Insight into the psychological and physical regression experienced through MND is offered through the poetry of George Macbeth, who died of MND and Anne Fisher, (undated) another victim. Macbeth (1992) writes about his total regression to a child-like status, with dependence and vulnerability (Appendix 1). Fisher's speech was quickly affected so she found poetry a helpful medium of self-expression (Appendix 2) as found in her poem ironically titled 'Voices'.

These two poetic contributions relate to the experience of MND but the search widened for accounts of being cared for in terminal situations. Explicit accounts have been published most notably by writers who have experienced caring themselves. These include Ruth Picardie (1998), John Diamond (1998), Robert McCrum (1998), and Jean-Dominique Bauby (1997). Although they were not MND sufferers they offer understandings of the experience of being cared for when suffering from terminal and/or debilitating conditions.

Ruth Picardie (1998) offers her account of dying from breast cancer. She gathers her e-mail messages to friends and her *Observer* newspaper entries, where she wrote about her experiences. Her journalistic flair and humorous writing holds the reader in tears from laughter and sadness simultaneously. She highlights medicine's limitations, the development of her own therapies, the paradox of denial and the wide-spread use of euphemistic language to cover-up the seriousness of her condition. The helpfulness of the love and wit of friends and family and the pain experienced through knowledge of the loss of her future. These experiences resonate with those encountered by the MND participants in this study.

Ruth learns to listen to her physical body and its failings against cancer which gives her truths before scientific tests validate her fears. She knows when the cancer is spreading before the doctors agreed to perform their radiological scientific tests.

Picardie (1998:30-31) writes,

'if they'd taken me seriously when I first reported the pain in my head, I could have had it all blitzed in one go… it just took me weeks to convince them I needed a CT scan because the X-rays aren't sensitive enough. I think from now on they won't fob me off'

This lack of professional listening to her instinctive self-knowledge aggravates and annoys her. It reveals to her a superior professional mentality that dismisses the person's judgement within the patient.

As treatments and therapies became less effective she finds her own in 'retail' therapy: expensive make-up, Channel 4's 'ER', 'Friends' and chocolate. Making herself feel better in the absence of cure, she approaches the living world through 'personal indulgence and escapism' (Picardie 1998:78).

Creating a normality and sense of control gives her more optimism and relief from her terminal condition than any thing else. Her essential desire for life allows her the paradox of denial in the reality she was facing, 'One way of coping is denial i.e. certainty that you are going to be one of the few that make it' (Picardie 1998:16-17) although with her odds of 18% for a five year survival, she knew the inevitable outcome. She found denial in health professional language, 'Cancer is all about fear, secrecy and euphemism - palliative care, advanced disease - all are euphemisms for dying. Oncology is the biggest euphemism in the world' (Picardie 1998:13). Ruth experienced her potential death a closed subject, put to one side by all concerned. This lack of preparation was a huge gap in her care provision, another parallel with the MND participants.

Death was not a taboo subject her. She and a friend dying of AIDS were able to share its preparation. Five months before she dies, she writes 'It feels good to have a friend who is sick too. God knows, I wish you weren't, but there's a level of connection that even the most supportive friends can't achieve' (Picardie 1998:6). However, this changes as death becomes more imminent, her choice of friends become more focused on healthy 'normal' activities. The living offer her hope to reach out for what is left in life.

Ruth explains that in facing death,

'What hurts most is losing the future. I won't be there to clap when my beloved babies learn to write their names; I won't be there to see them learn to swim, or go to school, or play the piano…' (Picardie 1998:58).

Ruth aligns waiting for death to pregnancy, 'the vomiting, the weird stuff growing inside you, the endless waiting for the big day….It's bloody tough living in limbo, not knowing exactly how long I've got left' (1998:58). She summarises how in her 33 years of life that 'It's just that I'll miss it so' (Picardie 1998:59). Her preparation for death was neglected by professionals as nobody supported her reflections to help her prepare for departure.

As I read this book after analysing the evidence from the MND participants the parallels were significant. The denial of the horror, the need for a normality, the lack of open discussion with professionals about dying, the stresses experienced from uncertainty as to when death will arrive, the importance of relationships and humour. The embodied knowing about self which often is not well received by professionals.

John Diamond, also a journalist, wrote of his experiences with tongue cancer in the *Sunday Times*. Diamond wrote claiming he could find no account of 'how would cancer affect me - what was it like to be a person with cancer, to deal with the pain and the fear and the anger?' (Diamond 1998:1). He found medical texts but little about the experience of being a person with cancer, hence his book 'Because cowards get cancer to' (Diamond 1998). He spares little detail of his experiences. His deep fear from the diagnosis was evident, 'while BUPA covers most contingencies, it doesn't cover fear' (Diamond 1998:31). It also does not cover the 'distrust' that is generated about one's physical body when diseased. He feels betrayed by his body which shows vulnerability in its life sustaining powers so he viewed it almost from a disembodied perspective. These two experiences resonate with the MND's 'existential shock', the loss of integrity of self through the 'struggle with increasing loss of control'.

Diamond raises two points about doctors and uncertainty. The principle of 'gradual disclosure which almost all doctors practise' (1998:63). Small pieces of information slowly emerge which leads to the next stage of treatment or prognosis. His second point is how disease follows an uncertain path with qualifiers being added all the time and every symptom changing the odds of survival.

Diamond also offers insight into living without speech after the formation of a tracheostomy. He found it frustrating that only his wife appeared to continue to understand his communication efforts. He writes of the link between communication ability and mental health, 'It was bad enough having a wonky voice but having a wonky voice and sounding like a stupid person was intolerable' (1998:211).

This also resonates with the experiences of the MND participants. In terms of relationships, Diamond reflects how 'it had taken cancer to teach me the basics' (Diamond 1998:240) to realise his depth of love for his wife and children. Although he identified that his cancer had not been a good thing he acknowledges how strange it was that it should lead him to think and feel with a new clarity, how existential considerations are provoked by extreme situations.

In a similar vein, the power of facing mortality reached Dennis Potter. In 1994, a few months before his death from cancer, Potter achieved a notable television interview with Melvyn Bragg. Drinking morphine and obviously in considerable paint he shone with his description of learning the meaning of the 'nowness' of life,

'the blossom is out in full now… it's a plum tree, it looks like apple blossom but it's white, and looking at it through the window when I'm writing, I see it is the whitest, frothiest, blossomist blossom that there ever could be, and I can see it. Things are more trivial than they ever were and more important…. The nowness of everything is absolutely wondrous, and if people could see that, you know' (Potter 1994:5)

This 'nowness' invokes a temporal realisation and a fresh perspective on life, a gain when facing one's death but also illustrative of the depth of emotions experienced under duress. Learning about caring from people in these extreme situations clarifies three areas: the emotional impact of life threatening conditions, the reflective depths that people enter and the need for other people to share their suffering. Yet in practice, the dying, terminal patient is still often the 'hopeless case', the 'failed cure' who is either sent home or if in a hospital setting is placed in a side ward. Questions emerge of Should all professionals be able to care for the person in this situation? How do professionals educated for cure adapt to such patient needs? In cancer care there are specific Macmillan nurses but what of neurological terminal conditions?

Robert McCrum (1998) and Jean-Dominique Bauby (1997) suffered cerebro-vascular accidents. This rendered Robert paralysed down one side and temporarily unable to speak. He survived the episode. Jean was immobilised and made mute as he had a brain stem accident. He managed to write a book through communicating with his eye lashes. He died the day after his book was published.

McCrum echoes Henke and Macbeth as he clarifies we are embodied persons but forget the significance of this in everyday 'healthy' life, 'As adults we forget that we live in our bodies. The unexpected failure of the body is a shocking catastrophe that threatens the flimsy edifice that we call the 'self', especially when one is reduced to the condition of a baby' (McCrum 1998:50).

He also echoes temporal uncertainty and fear involved in illness, 'no one was able to advise how long I would be incapacitated. This made things maddening, difficult, at times even frightening' (McCrum 1998:48). In his search for answers he met with vague statements about his progress which made him realise the limitations of medical knowledge. This is confirmed when one neurologist 'sheepishly confessed to me that doctors are actually quite ignorant about the brain' (McCrum 1998:48).

The effects of his disabilities made him realise he, 'was no longer the person I'd been twenty-four hours ago' (1998:13). This theme of change of Being remained as he called his situation 'My New Life' having left the 'Kingdom of the Well'. Being disabled in mobility and speech 'emphasises our solitude and isolation' (1998:46). Even surrounded by the love of his wife and parents this isolation existed.

His experiences of interacting with professional carers in hospital exists on a continuum. A nurse is described as his guardian angel who was kind, 'had a lovely smile and the most gentle manner' (McCrum 1998:20). However, he also explains how some nurses actually hurt him when completing lifting manoeuvres. As a passive recipient of care he has to learn 'to submit to the experiences' (1998:108). Being cared for puts one in a position of vulnerability, dependence and being controlled by others.

Bauby (1997) offers an incident which portrays the difference in perceptions between care professionals and a patient. As he was immobile he was introduced to a wheelchair.

To the therapist this was a functional achievement, to him it was a disaster, 'You can handle the wheelchair,' said the occupational therapist with a smile intended to make the remark sound like good news, whereas to my ears it had the ring of a life-sentence' (Bauby 1997:17).

Summary of the cared for experiences

Shocking catastrophe
Uncertainty
Lack of control
Dependence
Emotional liability
Remain a human, a person
Loneliness
Denial of death
Losing the future
Communication frustrations
New life in terminal disease
Vulnerability
Illness changes you
Temporal urgency of life left
Value tenderness, gentleness from others
Value love, family, friends
Isolation
Limitations of medicine/professionals
Embodied knowledge of 'self'
Fear
Depth of reflection when 'in extremis'
Different 'expectations' to professionals

2.3.2. Lay Carers

The title, lay carers, encompasses individuals without professional care education. In this study it includes people identified by the cared for as being their main lay carer, their spouse. Therefore, insights from spouses of the previously cited writers are considered.

Sarah McCrum offers extracts from her diary. She expresses aloneness in this new world of disability whilst trying to imagine what it must be like for her husband. She also experiences a loss of faith in the physical body,

'I keep wondering what it is like for him. I feel very alone and scared. I look at him - I know it's not fair - and I pray that his leg and arm will start to move again - right now...... I think I will always be afraid, for the rest of our lives' (McCrum 1998:99).

Her fear is not supported by professional carers. Her perceptions here are quite firm.

'I'm equally sure that they are uncompassionate, semi-aliens who just don't know how to deal with actual people. Maybe it's just too depressing for them giving bad news all the time, maybe it's easier to look at scans than to talk to patients' (McCrum 1998:112).

A neglected area of need is the needs of the lay carers themselves. On reading an entry of Sarah's diary, Robert reflects, 'People forget about the relatives of stroke sufferers. Of course they have their moods, too, and their own convalescent cycle of readjustment' (McCrum 1998:169).

Four months into coping with his stroke Sarah talks about the forced change in role she has been adopted,

'I have to adjust to my new multipurpose role: wife and lover and cheerleader and physiotherapist and cook and housekeeper and nurse and all round drudge. So I have to separate out my distaste of all that from what's happening with Robert' (McCrum 1998:181).

Sarah admits over time, how there is sanctuary in objectifying the extra work and responsibilities she now encounters. She forces these practical concerns as her new priorities over and above her emotional concerns about Robert. It seems as if she learns the extra physical efforts she is faced with can serve as a blanket or anaesthetic to her worries for her husband. Her emotional effects are harder to cope with than the physical aspects, particularly with the absence of support in this area for herself. She uses this reasoning to explain the outward behaviour of the professionals.

Matt Seaton, husband of Ruth Picardie, also offers insight into aspects of being a lay carer. He is faced with her death which has resonance to the world of MND. The disease affects their relationship towards the latter stages,

'In the last few weeks, when the cancer was rapidly advancing towards the ultimate Pyrrhic victory of killing its host, I often felt that, as Ruth was dying, our relationship was by degrees dying with her' (Picardie 1998:103).

He argues that dying is like a slow estrangement, it divides their relationship as it puts the diseased on one track to death and the lay carer on another track to bereavement,

'stretching our grasp of one another to the limit and eventually forcing us apart. In the end I could not reach her, and it felt like failure in me. And then she was gone' (Picarde 1998:104).

Similar disparate roads are pursued in the world of MND. The lay carers have to prepare themselves for loss and the prospect of a life alone.

Seaton was eventually faced with the need for institutional care for his wife. He describes how 'To have to put your 33 year-old- partner, your co-parent, your best friend, your peer and equal in every way, into care is pure distilled misery' (Picardie 1998:111). However, he did receive 'kind, patient and compassion guidance of the doctors and nurses there' (Picardie 1998:112). This quote supports the care receipt benefits offered by professionals educated in the process of dying, not only for the patient but also to relatives.

Summary of lay carers experiences

Adjustment to new roles
Loneliness
Love and empathy for cared for
Changing relationships
Adjustment to a new world of the sick
Wanting the best outcome
Emotional exhaustion
Lack of support for emotional reaction
Need for professionals to be educated in the way of dying
Wanting professional involvement

2.3.3. Professional Carers

Professional carers who have exposed their experiential world of working with those who suffer, need care and are dying are notable by their rarity. Two authors who have written are Elizabeth Kubler-Ross (1969) and Marie De Hennezel (1997). Their accounts both focus on their practices with the dying which is the link to caring in the world of MND.

MND leaves its victim with an average life expectancy of 3 months to 3 years. A care gap for the MND participants in this study was no consideration for the dying process and no access to hospice care. The lack of focus on care of the dying in MND is relevant to address and steers us to consider professional learning about care for the dying.

Kubler-Ross (1969), approached her work as a

'challenging opportunity to refocus on the patient as a human being....We have asked him to be our teacher so that we may learn more about the final stages of life with all its anxieties, fears and hopes' (Kubler-Ross 1969:11).

She describes the modern 'dying process' of being rushed into hospital and connected to a variety of technological devices; speed and energy are expended into decision-making, transfusions, infusion, ECG's and interventions to save your physical life.
There is not the same focus of energy for you as a feeling human being. She questions whether the focus on technology is a protective mechanism against our own anxieties about death. This question parallel's Menzies's (1960) conclusion about task orientated care from nurses. Do professionals need to busy themselves with tasks or technology to remove their own fear of being human, suffering, and death? In this context. Kubler-Ross (1969:23) considers the question 'Are we becoming less human or more human...? Whatever the answer may be, the patient is suffering more - not physically, perhaps, but emotionally'. The conclusion is that the balance needs to be redressed. She concludes that perhaps through gaining a greater understanding of the dying process we can learn how to engage and care better for those who are in this imminent situation and even learn to care more for ourselves.

She interviewed dying patients with the purpose of using the content with her medical students to help them learn from patients and to discuss how to share the news of a terminal disease with patients. During this process, she began recognising similarities of coping mechanisms in the dying experience and grouped them into five stages: Denial and isolation, Anger, Bargaining, Depression and Acceptance.

She learnt from dying people how considering her own death allowed her the freedom to engage with the death of another. Knowing a dying person allows the doctor insight into their strengths and weaknesses, experiences and problems in coming to terms with their terminal illness and subsequent caring needs. Kubler-Ross remained open to the critical realisation that death is natural and that technology has its limitations but more importantly that there is a human being in every patient. Keeping this focus on learning from patients and remaining in the human world allowed her to value the uniqueness of individuals. Her educational advice was to.

'teach our students the value of science and technology simultaneously with the art and science of inter-human relationships, of human and total patient care' (Kubler-Ross 1969:31).

Thirty years is a long time to have these recommendations before us. The evidence from this study serves to support her view and reminds us of the unfulfilled educational challenges to reach these goals.

A glimmer of hope is offered by De Hennezel (1997), who wrote 'Intimate Death' which documents seven years of her practice as a psychologist in a French palliative care unit. She reports the benefits of considering her own death to allow her the freedom to engage with the death of another. In her role with the dying, De Hennezel (1997:xii) writes,

'I do not know anymore about death itself, but trust my life has only increased. I am certain that I live more intensely and more aware of those joys and sorrows that I am given to live, and also all the little, daily, automatic things - like the simple fact of breathing or walking'.

She claims how difficult it is to explain death and how psychoanalysis has declared death to be beyond the reach of the mind and turned away from it to examine mourning instead. Her goal is to understand and be present with the dying: to promote engagement with the dying, to share their life with them through death, rather than be closed to fear, silence and isolation. These practices echo the needs of the previous autobiographies. She writes her book to,

'open up my readers' minds to the rich rewards that come from being there to share the last living moments of someone close to them....it has transformed my life.... Even when one enters final helplessness, one can still love and feel loved, and many of the dying, in their last moments, send back a poignant message: don't pass by life, don't pass by love' (De Hennezel 1997:xiv).

Summary of professional carer experiences

Ability to learn from patients
Need to know patients
Need to consider own death and work through this process
Need to balance technology with being human in educational programmes and practice
Awareness of the uniqueness of every individual
Awareness that as people we need to learn to live as well as learn how to die
Appreciate the impact of society's values on death and dying
Awareness of the importance of being in being human
The practice of being is as important as the practice of skills

Other accounts report on care professionals (Benner et al 1989, Lawler 1991 Smith 1992) which offer examples of intense commitment, sensitivity, relatedness with a pervading sense of humanity. These suggest that care professionals hold underpinning humanistic values of care. As Lawler (1991:vi) concludes from her study,

'This research has left me with a very profound and new respect for nurses. I have become deeply impressed with the extent of their sensitivity to the experience of their patients, and I have become even more sceptical about what the traditional logico-positivist science offers an occupation such as nursing'.

Her final remarks are particularly poignant to a study of care values. Although her suggestion is focused on nursing, it could be translated to all care professionals in that, 'what separates the (proper) nurse from those who are technically competent to perform nursing care is not what is done, but rather how it is done' (Lawler 1991:vi).

2.4. PERCEPTIONS OF CARE FROM THE KNOWLEDGE DOMAINS

This section considers literature from two major knowledge domains, philosophy and theology.

2.4.1. Philosophical Perceptions of Care

The early Greek contributions focus on virtues. Virtues are linked to care through concern. What one cares about becomes a concern and is therefore linked to values and subsequent behaviour. If one cares about respecting the confidentiality of others, then if a careless remark is heard it would not be revealed. This behaviour would indicate a virtuous character. Socrates' consistent aim was to learn how to live virtuously (Collinson 1987), which ultimately led to his death. He argued that each person seeks their own good but knowing what that good is, is the difficult question. However, once we do know, all wrong-doing is evil, knowledge is virtue and no one knowingly does evil. The connection between caring and goodness remains to this day but hides the bad that can also arise out of caring.

The relationship of virtues to social order can change through time and context as Macintyre (1985) reports.

Homer was dedicated to the notion of the warrior whereas Aristotle was dedicated to the notion of the Athenian gentleman. This example illustrates how virtues can be socially constructed through time and circumstance.

Aristotle's philosophy of virtue encapsulates the goodness or badness of the character of a person rather than whether they are right or wrong. Virtue is concerned with disposition of character (Scruton 1984). This meant that one was entitled to feel hatred and contempt towards those things which deserve it and remain virtuous. The link between care and character can be associated to this mode of thinking. This view considers care not as something that can be taught as it arises from one's character. However, Aristotle's teacher, Plato had argued that the just ruler is one who has philosophical knowledge of the good. Hence philosophers should be the kings, or at least the kings should become philosophers in order to ensure justice. In this thinking he sets out a rigorous education programme which can develop this just ruler and culminates in the knowledge of the 'Form of Good'. Justice, is firmly rooted as virtue and as an ethical ideal. The close correlation of virtue with goodness and ethics reinforces the importance of examining ethics and caring in more detail.

Thomas Aquinas (1225-74) was influenced by Aristotle's writing and is credited with combining them to those of the Catholic Church (Collinson 1987). Aquinas believed humans were their own authors of life and that they understood things through sense experiences and abstraction. Virtues were considered a person's firm attitudes and stable dispositions which required human effort to maintain, through intellect, education, deliberate acts and perseverance. In the Catholic Catechism (Chapman 1994) Aquinas is reported to have said, 'To love is to will the good of another'. The notion of virtues, do good, love another, are viewed as positive attributes are rooted in the character of a person but externally influenced. Although virtues do not directly include the concept of care, their connection with its underpinning values is clear. If character is considered the source of such virtues, promoting the continued development of caring could be enhanced through supportive measures such as faith, reason and education.

Care involves human interaction and so consideration is given to philosophical ideas in relation to what it means to be human. Descartes's (1596-1650) views are considered and these are followed by Heidegger's (1889-1976). Descartes laid down the philosophical foundations for the modern scientific age.

He reacted against 'the often vague misleading deliverances of our sensory organs' (Honderich 1995:189) and chose to find a system to reconstruct reliable knowledge. His system involved mathematics and reason and applied to 'matter' rather than 'thought'. This separation began Cartesian dualism, whereby he advocates 'the mind was wholly distinct from the world of matter… the mind .. is entirely distinct from the body' (Honderich 1995:191). This view of the person became known as the 'ghost in the machine' (Ryle 1949) and supported the development of science to investigate the machine (body) through a mechanistic lens. In this light, people were seen to have bodies that could be diseased. Doctors could be trained to understand the mechanics of these bodies and therefore offer a curative function. The role of holistic care for a person in this situation was threatened. Toon (1994:23) suggests it 'does not mean biomedical doctors are callous, but that caring is seen in a narrow, practical sense… Lack of sensitivity to human suffering is not intrinsic to it but, but the model may foster it'. The doctor-patient relationship has indeed been influenced by this body-mechanistic focus where scientific interventions can be objectively considered without emotion and suffering interfering in this process. As medicine emerged as the dominant health profession, this value has pervaded all other health professions.

Heidegger, a phenomenologist, presents three inter-related concepts which consider the person and care; 'Daesin', 'being in the world' and the lived experience. His notion of Daesin, means existence, or being involved in the world. Existence being the necessary precedent and enabling condition of thought is the reverse of the Cartesian phrase 'I think, therefore I am', (Steiner 1978:87). The Daesin has to make sense of itself when thrown into an already existing world. When a child is born he spends his life making sense of his surroundings, culture, existence, and purpose from his own developing experience base of being in 'his' world. In this sense, the idea of a self-determining, responsible being is consistent with Aristotle and Aquinas.

Heidegger uses Sorge, translated as care, to describe the prevailing attitude of Daesin. Sorge involves two strands; caring about (things) and caring for (people), but Heidegger considers care to 'be primordial and that it cannot be reduced to such phenomenon as willing, wishing, urging etc'. (Gelven 1989:122). Heidegger suggests that a human being has to be responsible for itself and involve itself in a concerned way, in the world it finds itself (Collinson 1987). Roach (1992) considers Heidegger's value of care is that of man's essential relation to the world to the extent that he interprets reality as care. Essentially though, Heidegger's care is the 'basic constitutive phenomenon of human existence.

It is thus ontological in that it constitutes one as human. When we do not care, we lose our being, and care is the way back into being' (Roach 1992:14). Bradshaw (1995:85) interprets Sorge as being 'I am concerned with me', a personal, self orientated concept. Macquarrie (1972) suggests the term concern has been used by existentialists to refer to the complex relationship designated by the 'in' of being-in-the-world, modes of concern by which man relates himself to his environment. This means that each of us is in continual pursuit of finding our own way of being in whatever circumstance we find ourselves.

Heidegger's meaning unravels care as a personal construction in pursuit of personal authenticity as opposed to practical knowledge. It is located in the context of the individual, in the individual's pursuit of making meaning in the world. It is not a moral or virtuous capacity or a dualism but it does have a sense of coherence for learning throughout life to make sense of the world.

A relational perspective of care is offered by Mayerhoff (1971) who argues that through caring for another there is a positive feedback. Giving through caring returns to the self by helping growth and self-actualisation 'I experience what I care for as having worth in its own right...apart from what it can do for the carer' (Mayerhoff 1971:8). This relational morality is a 'devotion grounded in the worth I experience in the other' (Mayerhoff 1971:10). Care is a desire, a moral interaction as 'I experience the other's development as bound up with my own sense of well-being' (Mayerhoff 1971:11). His being in the world in relation to care is actualised through personal growth whilst caring for others. However, where does this leave the unwilling carer?

2.4.2 Theological Perspectives of Care

The theological perspectives presented reflect Western concerns. The parable from the Christian Bible of the Good Samaritan is a central focus of Christian caring. The Greek word for care in the parable is *epimeliomai,* which translates as *'it matters to me'* (MacFarlane 1988:14). Four elements from the parable which mattered to the Good Samaritan are need, motivation, action and outcome. This is illustrative of the sense of mutuality in caring, the cared for receives and gains but so does the carer through giving. This parable mirrors patient-carer interactions. When a patient has a need, the carer has the motivation to care which leads to an action and an outcome. However, identification of need puts the action in an objective light. The need is treated rather than the person. The 'good Samaritan' leaves the patient after attending to the physical and financial aspects of need rather than being with and listening to his trauma. The idea of Greek virtue seems more influential to this parable than Mayerhoff's idea personal growth through caring.

Buber (1958) identified caring as a relationship with others. He values a religious existentialism which he centred on the distinction between direct, mutual relations (I-Thou or dialogue) and indirect utilitarian relations (designated I-It or monologue). In this perspective there is a distinctive moral element of recognising the value of being human and the associated behaviours thereof. This leads us back to virtues and phenomenology.

The relationship between professional carers and those whom they care for is examined by Campbell (1984) in his text, 'Moderated love. A theology of professional care'. He defines pastoral care as a kind of loving with the premise that care has one fundamental aim: to help people to know love, both as something to be received and as something to give. He draws on forms of love explicated in the bible: *eros* as the predominantly self-satisfying approach, *philia* as the identification with others and *agape* as the gratuitous concern for others welfare (Campbell 1984). Campbell highlights the physical aspects of care which the philosophers tend to neglect, as he considers actions to be imbedded within the 'being' of a person. He concludes that caring professions offer a 'moderated love', a combination of detachment to the individual although a concern for individual values, with a drive for socio-political change. Although he examines particular traits, histories and values of three professions he does not separate his conclusions. This aspect of Campbell's work supports commonalties of care amongst professionals rather than differences.

2.5. CARING PERCEPTIONS FROM PRACTICE-KNOWLEDGE DISCIPLINES

Caring professions have traditionally drawn upon knowledge disciplines to inform their theory and practice. The practice-knowledge disciplines considered in this section are psychology, education, sociology, ethics, socio-biology and anthropology.

2.5.1. Psychological perspectives of care

Psychology began with an objective approach to developing its knowledge base. The humanistic tradition emerged as a counter response and focused on personal growth, communication and counselling (Rogers 1967, Egan 1976). These theories and skills have informed professional carer education programmes where professionals have pursued client-professional relationships, as in nursing.

Techniques for caring communication (Egan 1976) are helpful but conversely can initially create distortion when a person is trying to remember how to sit, speak and develop a 'proper' caring communicative approach. If the essence of caring is about developing relationships with compassion and involvement of self, then more than technique is required. A meaningful genuine response is necessary which demands negotiation of complex situations.

Freud (1961), influenced by Heidegger's teaching, understands humans as being essentially self-serving, driven by aggression and unconscious forces that must be held in check although we appear to have an innate sense of caring when others are in difficult situations. In terms of personality, Freud described the id, ego and super ego where the id is innate, the ego rational and the superego ideal. All are linked to the mind's three territories of the unconscious, pre-conscious and conscious (Oliver 1993:25). Freud suggests a person's ability to care is a negotiated tension between these factions, an emotional labour between an innate selfishness and genetic imprint within a humanistic process.

Maslow (1962) identified two broad categories of need based on motives: deficiency motives (D-motives) and being motives (B motives). Deficiency motives preserve individuals and include physiological, safety, belonginess, love and esteem needs. Being motives focus on growth and personal development (Oliver 1993:72). Love and belonging needs lie in two categories: a selfish motivator (D-love) when an individual resorts to devious strategies to achieve tenderness and a more giving type love (B-love) which involves a more humanistic approach. These offer some explanation to tension between loving and caring. An overall lack of psychological understanding of care is highlighted by Hall (1990).

He identifies three reasons why more attention should be paid to care in a health context; first the limitations of cure, second that attempts of cure exist in a context of care and third the rise in chronic disability. He acknowledges the confusion and imprecision surrounding the word, recognising how 'it is as important to examine the beliefs, goals, practices and emotions of the carer as of the cared for' (Hall 1990:133). His 'four-component model of care' (Hall 1990:132) has echoes of Freudian theory:

1. care as a set of beliefs or philosophies
2. care as a set of goals or objectives
3. care as a set of practises and acts
4. the emotions and feelings which accompany care

Hall cites Wolfensberger's (1972) 'normalisation' view for professional care and Rayne and King's (1967) idea that care procedures should be 'inmate oriented' and not 'institutionally orientated'. He suggests lay philosophies of care are rooted in paternal and maternal models and, 'may bring passivity in the cared for and so encourage dependency' (Hall 1990:133). Hall's second category distinguishes between function (aims of actions) and topographical (form of behaviour) with appreciation of the neglect of the latter being obvious in the psychological literature due to the dearth of descriptions of caring. Direct caring practice and acts are attributed to the experience of informal carers where ten activities are presented, ranging from non-verbal communication to transmitting love and affection. His fourth category cites the Wagner (Hall 1990:137) report which suggests how caring,

'is frequently bound up with powerful and ambivalent feelings of commitment, warmth, love, guilt, anxiety, frustration, anger and sometimes sexuality'....but with negative aspects of... 'loneliness, exhaustion, stress, depression, resentment, anger, guilt, loss and grief'.

Although care can be discussed from a psychological stance, the development of a psychology of caring is far from being realised. However, its informing contribution to education is acknowledged through influencing theories of learning.

2.5.2. Educational perspectives of care

Education has been influenced by psychological theories from behaviourism to humanism. This latter category appears most relevant where the focus is on learning about self to promote authenticity to others and a sense of becoming. This perspective has echoes of Heidegger and Mayerhoff. Three important features of self and experiences in adult learning are identified, namely,

'subjective consciousness and awareness in knowing and acting; second, the process of 'becoming', of choosing ways of living that realise an innate, authentic self and third, the need to think holistically... a unity of feeling and acting' (cited in Usher et al 1997:96).

Dewey's (1964) personal growth theory makes the connection between education, being human and caring. He suggests, 'education means the enterprise of supplying the conditions which ensure growth, or adequacy of life, irrespective of age' (Dewey 1964:51). Education encompasses learning about self and other beings as well as particular skills to facilitate human interaction and care. He promotes personal growth as a necessary pursuit of being human and therefore necessary not only for people in extreme situations of impending disability and death but for everyone in all circumstances. Learning about ways of caring is central to being human. It can be argued that we all have the capacity to learn from, through and about caring but the significant variable is *what* we learn. In the lay world this is influenced by personal and contextual experiences but the agenda for professional care education is established from a power base of political, organisational and professional values of care.

Personal growth is envisaged as a moral stance by Jarvis (1997). He suggests there are three educational phases; the first being pre-knowledge which is learned through childhood, the second is the influence of values from society and the third is the relationship between intention and the action of becoming a moral agent.

Nurse educationalists have attempted to promote care as being at the heart of their curriculum through highlighting the caring imperative in education (Leininger and Watson 1990). These developments echoed nursing's claim to care as the essence of nursing (Benner & Wrubel 1989, Bishop & Scuder 1991, Roach 1982, Leininger 1980).

This reflects the vocational, oral history of nursing which traditionally promoted caring virtues such as service, compassion, commitment and dedication.

However, despite such literature, it is worrying that current nursing practices are increasingly being criticised for not offering clients the care expected (Phillips 1999) and that educational programmes appear to promote critical thinking, evidence based practice and competence (DoH 1999a, 1999b) over and above compassion, kindness, commitment and conscience.

Symanski (1990:137) states that 'care must be central in the curriculum' of nurse education. She offers five divisions of professional care that can be incorporated into educational programmes to foster the sense of care in practice.

1. Care as the art of nursing: developing expressive interpersonal acts of nursing: comforting, touching and being with another person. Paterson & Zderard (1988) emphasise interpersonal dimensions for raising awareness and coaching inter-personal engagement. Caring in this category is viewed as a humanising act, 'high touch' as opposed to 'high tech' (Henderson 1985, Kelley 1988, Leininger 1981).

2. Care as values and attitudes: related to interpersonal care behaviours. Ray (1981) proposed a care ideology that promotes growth in people as a form of love. Rieman (1986) supports valuing other human beings and Watson (1988) views care as a moral commitment towards preserving human dignity.

3. Care as action: Gaut (1983) considers how good intentions are not enough. There is the need for actions to bring about positive changes in the one being cared for.

4. Care linked with knowledge: Watson (1988) acknowledges the role and importance of the sciences and clinical topics as a presupposition for care; it is important to know what you are doing in practice.

5. Care as a substantive phenomena: Leininger's (1978-1988) work has been devoted to cultural aspects of care, the need to know people's ways of caring and being responsible and sensitive to these needs.

Education is essentially a practical activity. However, Jarvis (1997) reminds us that education is never neutral and values are present at every point of practice which may be ascribed by others. The values of behaviourism, humanism, personal growth and care are influenced by the culture and society of the time.

2.5.3. Sociological perspectives of care

It can be argued that human caring is as old as time itself, and therefore lay or social caring has the longest history of all. Most sociological investigations have concentrated on informal care. Literature on sociological perspectives of care are mainly related to social provision as influenced by economic, political and social action. Indeed there appears some confusion around the notion of care which includes nurture, treatment, protection of children, accommodation for the frail and disabled, and custody for the disturbed criminal. Within this broad company is a confusion about who lay carers are, as there are those who can be paid, those who are unpaid, volunteers, relatives, women, men and children.

Groups in society who need caring have a history of continuing disadvantage. These groups illustrate society's devaluing of people who need care which include the elderly, mentally ill, people with learning disabilities, physical disabilities and the chronically sick (Dalley 1988). Pinker (1979) traces society's devaluing of people in these groups during the nineteenth century with their drift into workhouses. As voluntary hospitals began to develop as curative centres of excellence this left non-curative people possessing little medical interest. This left their caring to 'lay' carers rather than professional carers.

The White Paper (1981) on the elderly stressed care in the community must increasingly mean care by the community (DHSS 1981). This shift was preferable by most families but was not accompanied by a shift in resources and provision (Neale & Clark 1992), or a shift in attitudes towards informal carers from health carers. Resources are controlled through political and economic factors but in terms of attitudes to informal carers and caring itself, this has its own legacy.

The 1990's saw a government explosion of concern for lay carers in policy documents. In reality although their visibility may have shone through, 'policy itself has not engaged in any substantial way with their incorporation, remaining undeveloped and seldom going beyond bland statements of the importance of supporting carers' (Twigg & Atkin 1994:1). However, in 1995 the Carers (Recognition and Services) Act finally recognised the role and contribution of the carer promoting the statutory right of carers to an assessment of their ability to care. The Act placed a duty on local authorities to take account of such assessment when deciding what services they should provide. 'Modernisation' is the focus of the current labour administration in the UK. Their espoused vision is of an NHS where services are shared around the convenience of patients (Milburn 1999). Perhaps this vision may also extend to the inclusion of lay carers but at least it illustrates a move towards centring need to clients rather than providers. This area requires intervention as Nolan & Grant (1989) report the needs of informal carers are a neglected area of nursing practice which can be applied to professions allied to medicine. Clarifying the values of professional carers may help shed light on this problem and help plan solutions.

Sociologists have a developing literature base devoted to investigating unpaid carers in the community which Twigg and Atkin (1994:1) report offers a 'good understanding of caring - its origins, incidence, patterns and experiences'. They go on to suggest there are gaps in our understanding concerning how carers are perceived, how carers fit into the service system and what assumptions are made about carers. However, there is a wealth of evidence to suggest that the majority of lay carers are women (Henwood 1998). This led to interest in this area from feminists and to arguments that 'care in the community' is an exploitation of women.

2.5.4. Ethical and feminist perspectives of care

Ethics is the study of values with rules or principles for guiding judgements as to what is right and wrong. Cooper (1991) suggests there are two moral frameworks which are in creative tension. The first framework engages ethical principles and is the basis for biomedical ethics (Beauchamp and Childress 1989), the second focus is relational, as in caring ethics (Gilligan 1982, Noddings 1984).

The biomedical model is coherent with Kohlberg's (1986) work on stages of moral development which is claimed to be a more male orientated vision of the world. It focuses on cognitive processes and does not include affective dimensions. Kohlberg's work led to an assumption that moral judgement is based on rights which 'seeks abstract laws and universal principles which will settle disputes impartially, impersonally and fairly' (Jarvis et al 1998:69).

These views correlate to the current biomedical ethical principles of respect for autonomy, beneficence, maleficence and justice (Beauchamp and Childress 1989) which dominate professional health care practices and decision making. Cooper (1991:23) reinforces that the person using this model for ethical decisions, 'assumes a position of detachment.......ensures objectivity and impartiality'. This linear approach has its strengths in objectivity but not all situations are rule accepting.

Caring ethics offers an alternative stance whereby moral concern is with needs and corresponding responsibility as they arise within a relationship (Cooper 1991). A moral response in this sense is not linear, objective and detached but individualised, subjective, circular and guided by caring for another. Nursing has been influenced by both frameworks; formally by the biomedical model due to the influence of medical science and experientially by caring ethics as its practice is rooted in 'concrete relationships and care' (Kuhse 1997:143). Medicine has almost exclusively been influenced by the biomedical model.

Gilligan, (1982) through investigating women's ways of moral development found differences in gender upbringing which she claims affects social learning about values. These differing social learning experiences led to different ways of personal development and values. Males learn to value separation, self-esteem, skills and knowledge, abstract rule-governed thinking whereas females values relation, connectedness, responsibility to others, understanding with an emphasis on experience. These two contrasting approaches highlight her theory of 'different paths of development....the different ways in which the experiences of separation and connection are aligned with the voice of the self' (Gilligan 1982:39).

Indeed her data suggest that 'rather than linear development, it may be more appropriate to see women as engaged in cyclical confrontation: moral values stressing altruism and connection' (Davies 1995:26). Gilligan's findings propose that women's learning is different from men's but although she sets out to state the 'different voice' through gender differentiated research, she attempts to offer her findings as 'a distinction between two modes of thought and to focus a problem of interpretation rather than to present a generalisation about either sex' (Gilligan 1982:2).

Noddings (1984) took Gilligan's work further to apply social learning to caring ethics and its practice. She believes the primary aim of life is 'caring and being cared for in the human domain... A life meeting this aim is - despite pain, deprivation and trouble - filled at least occasionally with joy, wonder, engagement and tenderness' (Noddings 1984:174). To appreciate and fulfil life's aim caring needs to be the primary aim of education. The educator therefore needs to practice caring, whether that be towards the human audience or towards the 'craft' or knowledge that is being discussed. In this argument, caring is the dominant way of being and way of action.

Three features of the ethic of care are identified by Noddings: receptivity, reciprocity and connectiveness. These features highlight a circular connective way of being as opposed to the linear decision-making approach of biomedical ethics. She suggests caring processes are cognitive not emotive with the situation of caring being tied to a particular context. In the process of being the one-caring she states that if this person is not cared for then the caring cannot be maintained. This has implications of mutuality; the cared-for has to be alert to the needs of the one-caring for a successful relationship to continue.

Noddings aligns this way of caring to the ideals presented by Mayerhoff and Buber, which she calls engrossment and displacement of motivation. She dismisses her critics of this approach (Hult 1979) in terms of demanding time and the depth of relationship required through establishing that such an encounter can be brief even though 'the encounter is total' (Noddings 1984:180).

Gadow (1990) considers care from an ethical perspective rather than creating an ethic of care. She argues that caring and scientific objectivity are opposites; caring pivots on the moral principle of regard for persons as subjects rather than objects. This stance is congruent with Buber's relational contribution. She contends that nursing (one could include other caring professions) demands a subjective involvement with patients which is governed through the nurse's (practitioner's) own embodied experience; thereby reducing the likelihood of objectification of either the patient or the nurse herself. However, no explanation is offered for cultural/external pressures that nurses and other health carers experience such as economic constraints, personality clashes and self-protection (Melia 1987) which may encourage objectivity in their caring and give rise to patients being known as 'the man in bed 12' and thereby reducing the subjectivity ideal.

Gadow's (1990:34) thesis is 'caring as advocacy, the protection and the enhancement of patient subjectivity'. This requires commitment to subjectivity whereby caring involves assisting patients to reach decisions that express their own values. She particularly takes up the mantle of promoting this stance for patients who cannot express their own subjectivity. She calls such patients silent patients as Gadow acknowledges that even if communication is a hurdle their competence may not be compromised; this situation is particularly relevant to people with MND. She rejects using utilitarianism and beneficence principles in these situations as Gadow regards these as promoting the objective view of persons.

Her argument suggests that we learn bodies are objects, things. We treat the broken arm as a broken thing, we inflict pain on a body to help cure it and as health care professionals we disembody ourselves in order not to suffer with the other body that is in pain. Access to the patient's subjectivity however, is to bridge the chasm between the patient and themselves to become re-embodied themselves so they can experience the patient's body as a subjective being rather than a thing. This opens up the nurse to being vulnerable and unprotected from the patient's pain. It promotes involvement with another human being in the sense of 'being human' and then allows judgement in the difference between harm and benefit in actions. This state, when interacting with silent patients, keeps their subjectivity to the fore and promotes the carer to engage and action care with the person. Gadow suggests that such embodied involvement can allow the nurse to know the patient, not in the literal sense but in an interpretative sense;

'Hedged with ambiguity though the nurse's translation may be, it is the only way in which the silent patient's subjectivity is given voice. And it is only possible when the nurse's voice arises, like the patient's, from the depths of embodiment' (Gadow 1990:39).

2.5.5. Socio-biological perspectives of care

Socio-biology is an 'emerging discipline which deals with the extent to which genetic factors influence or control patterns of behaviour as well as the extent to which patterns of behaviour, in turn, influence or control genetic evolution' (Fetzer 1985:ix). Wilson (1988) was one of the leading socio-biologists who initiated the idea that humans think and act in ways constrained by certain innate characteristics: epigenetic rules.

He considers that human culture and knowledge claims are adaptations of the species to ensure its survival through multiplication of the genes. He suggests that genes have a control factor over the development of culture (Wilson 1988), insinuating that what we learn. how we adapt, and the notion of causality in natural science are all useful strategies to promote our survival. He also adds that principally the human mind has developed for survival and reproduction. so reason is just one techniques to support these aims (Wilson 1988). The use of reason for promoting care amongst human beings is therefore for protection and promotion of the species. This argument could lay the ground for justification of the possibility of care being a genetic trait. It would then have to argued that this genetic trait can be over-ruled by other genes in certain circumstances as although care can be considered a cultural imperative and like-minded groups of people may well care for each other, there are many situations when care is over-ridden, as in one group of humans attacking another.

If Wilson's premise considers caring is biologically programmed in human nature, meaning care was designed through evolution, this leads to the possibility that one day a 'caring gene' may be discovered. A rationale for the biological programming of caring or 'social co-operation' is explained by Thomas (1985:122) 'social co-operation plays a pre-eminent role in the survival or, at any rate, the betterment of the human species'. Thomas highlights the amount of care and attention off-spring require to illustrate the necessity of human beings to live in this way and even argues how 'having the capacity to act morally, is favoured by evolutionary biology' (Thomas 1985:123).

However, he does concede that even if we are biologically programmed to have certain dispositions, 'it is quite another to say that they will be actualised' (Thomas 1985:125) as the effects and influences of others and the environment all pay their part. Following this line of argument if we have not the moral example through role modelling, parental example or significant others then the biological programmed morality can be diminished and new ways of being learnt. These ideas can be linked back to Greek virtues of character and learning potential for enhancement of caring. This could also explain people's uncaring behaviours towards others.

2.5.6. Anthropological perspectives of care

If there is an assumption that caring is a genetically programmed disposition, albeit in a variety of 'strengths', this approach concurs with that of social anthropologists who highlight the naturalness of nurturing or caring behaviours.

However, in anthropological terms it is useful to consider beliefs about illness before considering beliefs about caring in illness as if 'health care is sought, the definitions that the lay person brings to bear on his or her illness constrains the kinds of help sought and the perceptions of benefit gained from treatment' (Fitzpatrick 1984:11).

Chrisman (1977) offers a framework from a cross-cultural evidence of folk ideas about illness consisting of four logics; degeneration; mechanical; balance; invasion which may vary in importance from one culture to another. Fitzpatrick (1984) suggests there is a tension in western lay beliefs of illness which are dominated by causative factors of stress, worry and tension (inherent in Chrisman's balance logic).
Whereas the dominant approach to health and illness is biomedical this has little room for the social, psychological and behavioural dimensions (Fitzpatrick 1984:17). Lack of attention to patients' meanings and interpretations from care professionals is proved to be problematic for some patients.

Bloom and Monterossa (1981) identified a group of people who had been told they were hypertensive, only later to discover they were not. These people were found to have more depressive symptoms and a lower general state of health than a comparison group which could only be attributed to the impact of being labelled hypertensive. Addressing the meanings behind labels is therefore an important part of health care.

Reassurance is a lay need which is often sought by patients. Fitzpatrick (1980:28) suggests two ingredients for effective reassurance; first is information and second is appreciation of the affective meaning of symptoms gained from prompting questions such as 'Tell me more about the way this symptom worries you'.

There appears a dearth of research literature in the experience of illness. One source is Morse and Johnson's (1991) book entitled, 'The Illness Experience, Dimensions of Suffering'.

Patients' experiences of adjusting following a heart attack, having a hysterectomy, leaving a psychiatric hospital and husbands' experiences during their wives' chemotherapy are documented. From these collective research projects, Morse and Johnson offer tentative suggestions for a theory of illness, The Illness Constellation Model. In terms of motor neurone disease, no illness perspective been researched to date.

Understanding how different cultures hold and action their caring values has been a major plank of Madeleine Leininger's work as a nurse researcher and anthropologist. Her main argument is that there is very limited content about the ethical and moral dimensions of culture care taught in schools of nursing, (Leininger 1990). She has tried to address this through her own work and the theoretical development of the 'Culture Care Diversity and Universality Model' (Leininger 1988).

2.6. INFLUENCES OF KNOWLEDGE LAYERS ON THREE CARING PROFESSIONS

Having considered care from knowledge foundations and practice knowledge disciplines, it is useful to consider the influences these layers have had to three major caring professions; nursing, medicine and social work. This choice is not privileging these professions over others but offers a manageable range for consideration. Four value layers are identified; *virtues and character* which affect professional rules of engagement and trust, *Cartesian dualism* which affects the view of the person and therefore caring values and practices; *relational values and personal growth* which are rooted in phenomenological and hermeneutic philosophies (also influenced by socio-biology and anthropology), together with educational and psychological humanism, and *ethical values* in terms of moral dimensions of being human with values to appreciate goodness and rightness. As nursing has laid claim to care whereas medicine is traditionally rooted in cure and social work in welfare, the majority of care literature in this section focuses on nursing.

Virtues and character

Aristotle's philosophy of virtue is concerned with the disposition of character in terms of goodness or badness with a positive valuation on being good. Socrates believed that once good is known then the challenge is to learn how to live virtuously.

Aquinas combined virtues, a person's firm attitudes and stable dispositions, with a need for education and coaching, as effort is required to maintain them. It can be argued that these values have influenced professionals to be of good character which is kept in check through obedience and duty and promotes the award of trust from clients.

Kitson (1993:29) identifies 'caring-as-duty' which traditionally involved a hierarchical system of control and subjugation of emotions. It accentuated professional distancing from patients and clients and placed obedience and obligation to higher authorities as priorities. Expression of these values involved dedication and devotion to duty, always putting other peoples needs before ones own. This legacy remains whereby doctors and nurses are expected to be virtuous, they are trusted by their patients who expect them to care for them in times of disease and illness.

Social work can be said to be founded on philanthropic ideas but rooted in welfare rather than medicine (Downie and Telfer 1980). Trust needs to exist between social worker and client but social workers have to operate within legal precedents. It can be argued that the sense of duty is in tension between duty to the client and duty to the law.

Cartesian dualism

Van Maanen (1990:914) suggests, 'Nursing and Medicine are the products of Cartesian thinking that has fragmented our perspectives on man and his living world. The consequences of this scientific perspective are reflected in all aspects of life'.

Care in this regard has been converted into privileging cure and narrowing care to this cure position. The biomedical mechanistic view of the person has dominated the education preparation of nurses and doctors to value cure over care. This situation places them both in a dichotomy. Their knowledge base is rooted in 'facts' but their practice is rooted in human suffering and interaction. Social workers are grounded in law, sociology and policy so they also have facts and contextual human interactions.

Menzies (1960) revealed a 'social defence system' in her classic study of nurses behaviour, whereby nurses did not develop close relationships with their patients but suppressed their feelings and emotions in the face of great emotional distress and suffering all around them.

The nurses shouldered their feelings of anxiety as guilt and personal failings. Nurses were caught between the suffering of the patients and their own, they were in a state of not belonging due to a suppression of their own values. It can be argued that applying facts to diseases and remaining withdrawn from the complex individuality of patients is safer for practitioners. This situation is enhanced if the educational input is rooted in the scientific world of biology and chemistry rather than the complexity of being human. Caring in this sense is motivated towards healing the body.

Over the last 30 years, nursing has claimed care as the essence of nursing (Benner & Wrubel 1989, Bishop & Scuder 1991, Roach 1982, Leininger 1980). They have attempted to detach themselves from the Carteisian and medical approach to either return to female orientated values of care (Noddings 1984) or construct distinct models of nursing. Morse et al (1990) report how practical caring intervention were also seen in a new light as being 'therapeutic' (Gaut 1983, Swanson-Kauffman 1986). They suggest caring actions may be specific such as attentive listening, teaching, advocacy, being there or caring may include all nursing actions that enable or assist patients. Nurses accepted the importance of knowledge and skills as their foundation to enable action in a caring way.

Medicine also began to challenge the mechanistic approach to their practice. Toon (1994) reports on the Balint movement of the 1950's which responded to the perceived inadequacy of the biomedical approach in general practice. The Balint movement recognised that 'illness cannot be dealt solely in terms of the dysfunction of a machine but needs to be viewed more in human terms' (Toon 1994:26). Practice was promoted to focus on the illness as well as the disease which changed the doctor-patient relationship from an 'impersonal technician with a machine to a personal relationship between two human beings' (Toon 1994:26). This drive to reject Cartesian values in the inter-personal dimension has grown steadily in medicine during the last 40 years. Developments have affected the addition of inter-personal education and training in medical education programmes even though these may be regarded as 'soft' knowledge (Curzen 1991) and secondary to 'hard', objective knowledge.

It can be argued that social work is a system of promoting social control through controlling people as objects. Downie and Telfer (1980:15) suggest it is 'aimed at preventing revolution by providing palliatives for the worst miseries and so distracting the attention of the unfortunate from the basic injustice of the present system'. This perspective appears to value the person as an object to be controlled rather than a person to be cared for.

In this same light, Twigg (1989) recognised that informal carers are not perceived by professionals as co-clients, patients or even co-workers, but as resources which are not substituted for. This situation leaves informal carers in very difficult circumstances. Henwood's (1998) report on carers experiences of the NHS is entitled 'Ignored and Invisible?' She documents how lay carers are treated by professionals and how attitudes are hard to change even if there is legislation. She found that 'three quarters of the carers who responded to the survey were caring without any regular help' (Henwood 1998:3).

Relational values and Personal growth

Relational values in care are stated by Mayerhoff (1971) and Buber (1958). Mayerhoff (1971) argues that through caring for another, the action and feelings have a positive feedback. Giving through caring returns to the self by helping growth and self-actualisation. Buber (1958) focuses on disposition of one person to another in the I-thou and I-It perspective. Socio-biology and anthropology suggests care is innate as it is a requisite for human survival through co-operation. Personal growth also has a self-determining aspects through life relations, not just people relations.

Heidegger suggests a person has to make sense of itself when thrown into an already existing world. In this sense, the idea of a self-determining, responsible being is consistent with learning for personal growth. Heidegger labelled care as Sorge, a personal construction in pursuit of personal authenticity. His is not a moral or virtuous capacity but supports the individual as being the centre of their own meaning construction.

The rise of the therapeutic nurse-patient in the 1950's drew upon theories of psychoanalysis, psychotherapy and the philosophy of phenomenology. These are also linked to personal growth theories in education. Nursing was beginning to be theorised as differentiated from medicine, it was attempting to develop itself as a discipline. Protagonists of the caring as therapeutic relationship were Leininger (1988), Watson (1979) and Roach (1992) who were moving from the needs based theories of nursing to the interactionist theories of King (1971) , Orlando (1961), and Paterson & Zderard (1988).

The move was to encourage nursing to be based on transpersonal care, to encourage relationships to be formed on respect for persons, understanding, empathy and warmth to practice with a non-judgemental attitude. The values of the therapeutic relationship are in stark contrast to the social defence system. This shift results in two conceptualisations of caring running in tension with each other.

Morse et al (1990:5) identify a caring epistemological perspective in the relational field called caring as an affect. This involves caring with 'emotional involvement with or an empathetic feeling for the patient experience' (Morse et al 1990:5). The nurse is encouraged to act selflessly and with caring feelings towards patients. Potential dangers of personal vulnerability then arise when there is not enough time, staff or liking of all people. The nurse-patient interpersonal relationship stance (Knowlden 1988, Weiss 1984) believe the nurse-patient relationship is the essence of caring. The relationship (feeling) and content (behaviour) of caring show concern and health teaching.

Another caring epistemological perspective (Morse et al 1990) is caring as a human trait. This is grounded in socio-biology as it rests on the assumption that all human beings have the potential to care although this potential is not uniform. Roach (1992) suggests a contributory factor in this situation is related to one's own experience of being cared for. In nurse education terms, caring is mostly taught as skills and knowledge which assumes an affective component but this is usually implicit rather than explicit. A caring approach to personnel is not always explicit in education or organisational delivery.

Campbell (1984) concluded in social work there is a focus of enabling client self-determination through support and encouragement. This moves people from being victims to taking control of circumstances through hope and expansion of viewpoints through this caring approach. However, social work practice is at the intersection of the personal and the political. Three main groups can be described including; radical, personal and mediation social workers (Campbell 1984). The first group are expected to be political activists to change the inequalities created by capitalist society. These are held to account for the continuance of vulnerable groups due to the promotion of individualism in capitalism and personal effort for success; the second group are expected to focus on individuals to promote purposeful and ethical application of their personal skills in interpersonal relationships towards enhancing the personal and social functioning of an individual; the mediation group adopts an advocacy role on behalf of the disadvantaged.

Within these three approaches, Campbell (1984:66) argues the 'problem is to define social work interventions which are caring, but not meddlesome or manipulative. People who seek assistance may find their problem redefined by those who feel they know better' .

Ethical values

Caring-as-ethical was espoused by Benner and Wrubel (1989). This move was influenced by ethics, virtue ethics and moral development theories of Kohlberg (1986), Gilligan (1982) and Noddings (1984). Caring-as-ethical can perhaps been seen as complementary to the relational approach but also has some closeness to the duty aspect.The emphasis is for relationships to be held on mutuality, respect for persons and client empowerment. However, this moves into the difficulties of control versus care and autonomy versus intrusion.

Morse et al's (1990) fifth caring epistemological perspective is caring as a moral imperative or ideal. It reports caring as a fundamental value or moral ideal (Morse et al 1990:40). Protagonists of this view are Gadow (1985) and Watson (1985) who consider nursing is about preserving the dignity of patients which is not linked with tasks or behaviours but commitment to maintaining an individual's integrity and dignity. Caring in this sense again becomes a duty which rests uneasy in a society that does not explicitly value caring.

2.6.1. The gap in influences

Nursing is the only one of the three care professions to claim some sense of ownership of care, as the other two professions carved their sense of discipline not from care but from cure and welfare. Although four value positions have been identified as influential to professional practice, the question needs to be asked, 'Do any of them match the values of the cared for and lay carers? A tentative response at this stage is the apparent consistent neglect to take into account the lived experiences of the client narrative, the lived experiences of those receiving the care to influence the values of the professionals.

The experience of informal carers providing nursing support for disabled dependants was investigated by Atkinson (1992). He identified informal carers were providing the majority of nursing support which involved technical procedures as well as personal care.

Lack of appreciation of the lived experiences led him to conclude, 'that there is scope for professional nurses to make a greater contribution to the support of informal carers, particularly by regular review of the nature and level of assistance which carers provide' (Atkinson 1992:835).

Von Essen & Sjoden (1991) found significant differences between perceptions of caring behaviours between nursing staff and patients using a modified CARE-Q instrument. Nursing staff ranked expressive/affective behaviours as most important whereas patients ranked honest, clear information and competent clinical expertise as most important. This outcome encourages the search for differences which may be in values of caring.

Caring and non-caring nurses were the focus of Rieman's (1986) study . She asked patients of their experiences of both. The patients focused on the presence or absence of inter-personal interactive dimensions as caring takes place in a relationship. The cared for is the reason why caring exists and it is their difficulties which focus the relationship into a caring one.

The autobiographical literature presented at the beginning of his chapter highlights the importance of the need to give voice to clients and lay carers existential experience of care in illness, which this study intends to pursue but in tandem with the voices of the professionals.

2.7. SUMMARY OF CHAPTER

This chapter has presented layers of thinking about care through autobiographical and theoretical literature. The contributors to our understanding of this phenomenon have been drawn from a wide experience base inclusive of philosophers, theologians, educationalists, sociologists, psychologists, ethicists, socio-biologist, anthropologists. Their influences have been located in the world of professional care.

What remains unknown is the specific value base of three groups of people involved in caring in the world of motor neurone disease. Is there a difference in their value base? What are the main value influences on professionals, lay carers and the cared for? Is there a difference in the practices of care delivery and care receipt between the three groups? How these questions can be addressed is explored in the next chapter.

CHAPTER 3: METHODOLOGICAL DECISION TRAIL

3.1. INTRODUCTION

This chapter consists of four main parts. First the research question is established in the context of choosing the interpretive research paradigm. The two theoretical frameworks which support the study, through application of their principles and metaphors, are phenomenology and hermeneutics. These are considered in turn when their frameworks are historically situated and discussed to highlight the connections between investigating phenomena, ways of being, lived experiences and interpretation, to illustrate their application to the context of the study. Third, the construction of the analysis process is clarified, and fourth, issues of establishing rigour in the research study are discussed.

3.2. THE RESEARCH QUESTION AND CHOOSING THE PARADIGM

Research is a term known for various approaches to generate knowledge. The choice of research approach, its informing philosophical framework or methodology and subsequent design, should be compatible with and governed by the research question. The central research question in the study is: 'What are the lay and professional values of care in the context of motor neurone disease and is there a difference between them which affects care delivery and receipt?'. To frame the direction of this question, three additional aspects are identified;

i) What is the experience of living in the world of motor neurone disease?
ii) What does care and caring mean to people with MND, their lay carers and their professional carers in the context of motor neurone disease?
iii) Can a greater understanding of lay and professional caring values influence health care practices?

One therefore needs to chose a research approach that captures people's lived experience and gains a sense of meaning within the specific context. Wilkes (1991:231) suggests three broad research paradigms, or three cognitive interests which guide knowledge development as devised by Habermas (1987). They are identified as the positivist, interpretive and critical theory approaches.

It is recognised that nursing (and education) has no unique research tradition (Donaldson & Crowley 1978), and that the solution is to borrow approaches and methods from other more established disciplines. Therefore it is useful to consider these three paradigms. in the context of the research questions being asked, to rise to Munhall and Oiler's (1986:48) conditions which state how congruence 'between philosophical frameworks and research approaches is understood to be a necessary condition for scholarly achievement in nursing'.

3.2.1. Choosing the research approach

Research problems in the positivist paradigm are suited to situations in the natural world rather than human experience. This positivist approach for the generation of knowledge has carved itself as the 'dominant' approach in Western culture. Indeed, one could go so far as to state the word 'science' has become the euphemism for positivist approaches to developing knowledge. Although this is a very successful approach to uncovering knowledge it is important to appreciate that one method alone cannot answer all questions.

Cohen & Manion (1994) consider the positivist approach is limited by suggesting only sensory experiences can form the basis of valid knowledge. Claiming knowledge can only be advanced by means of observation and experiment, testing theory and using quantitative approaches involving controls and variables, conducting experiments and prescribing meanings is restrictive. Results are usually statistically portrayed and knowledge is assumed. The research question in this study does not claim a known hypothesis, is not attempting to test a hypothesis. Rather it aims to unravel meanings that people make of their experiences within a specific context, to gain understanding about people's ways of being and their guiding values. The positivist paradigm therefore is not congruent to these questions.

The interpretive paradigm developed as a result of dissatisfaction with the positivist approach for certain questions (see section 3.3). This led to a shift in philosophical thinking. Carr & Kemmis (1983) summarise these concerns through suggesting that human actions cannot be observed in the same way as natural objects. Human beings can only be studied from the point of view of the actors, their motives, intentions and purposes. Phenomenology offers a stance for describing and examining human experiences and hermeneutics contributes to the idea of interpretation from different perspectives, that is 'situated' understandings.

Listening to the lived experiences of the cared for and their carers permits the researcher to begin an interpretive journey. To inductively appreciate and gain understanding of living and caring in the world of motor neurone disease. From listening and interpreting caring stories, through being with and interacting with groups of people involved in caring, the researcher is open to new experiences and new understandings. This can lead to an understanding of care in a specific context and appears supportive of the research questions in this study.

The third approach to knowledge generation, as identified by Habermans (1987), goes beyond the positivist and interpretive approaches and aims to integrate theory and practice. Critical theory considers the positivist and interpretive paradigms are both privileged concepts which promote the binary of opposites. That is objective over subjective, with the latter in the more inferior position. Both value rationality and reason and tend to seek generalisations rather than competing claims. Critical theory assumes the world is more complex than this, it seeks to criticise incongruities and contradictions in people's lives through focusing on critical self-reflection, coupled with action and change (Wilkes 1991). It can be argued that before this approach can be adopted, an understanding of the particular world is required. Applied to this study, an understanding of caring in the context of MND needs to be established before it can be critiqued. However, once the understanding is exposed then it can be deconstructed, criticised and a new perspective emerge.

The most appropriate research approach for the posed question therefore lies in the interpretive paradigm. The pilot investigation supported this decision with the following observations. Whilst listening to the carers and cared for talk about their experiences, I recognised that the only way I could make sense of their stories involved two stages; first to draw on my own experience of care as a person and a nurse and secondly through on-going dialogue with the participants to seek clarification of my interpretations. As I immersed myself in the world of neurological disability I appreciated a transformation of my understanding of caring. The dialogue between us allowed exchange of meaning. Sometimes I needed further explanation to help me understand. This meant I altered my initial interpretation.

During my interactions with people suffering from motor neurone disease, I quickly learnt that the participants presented themselves differently according to their situations. The cared for had to learn how to manage their distressing and demanding circumstances, the lay carer was adapting and learning to care and the professional carer was offering her expertise.

As the researcher I experienced many emotions in my interactions with them, particularly the lay participants. I was often moved, felt privileged, uncomfortable, saddened and sometimes surprised by their stories. These personal reactions allowed me to appreciate how my own experiences of life, of suffering, joy, pain, caring and potential death were influential to my understanding and interpretation. Three learning aspects from the pilot investigation are summarised and are related to the different stances of the three participant groups;

a) I recognised how the 'cared for' were mostly independent people who had to change their life style as the disease progressed and to prepare for their own premature death. They had to learn how to be cared for (or not), and indeed teach others how to care for them. Their stories and presence made me realise the suffering they endured and how out of control and dispirited one could easily become. This was learning about situations beyond my experience.

b) Lay carers allowed me to appreciate their high demands when challenged to care for a loved one and the learning they had to quickly achieve to cope (or not). This made me question my own resources and values as to whether I could learn to manage to care if placed in this sort of situation.

c) As I talked with the professional last, I appreciated how I had been influenced by the previous participants, whereas before their perspectives were less clear. I was able to understand how a professional can become immersed in their own world rather than remain open to the worlds of the people they are caring for. I considered my own professional experience and how I may have assumed I was thinking of patients but not knowing their worlds sufficiently to understand them.These initial three learning outcomes established the efficacy of phenomenology as the appropriate framework and encouraged further searching in this field.

3.3. PHENOMENOLOGY

The term phenomenology has a tortuous history and little homogeneity. Gelven (1979) traces the origins, developments and protagonists of phenomenology as beginning with Kant in the 18th century. He distinguished between *phenomenon* (things as they are known to us through the senses) and *noumenon* (things as they are in themselves, unknowable). Hegel (1770- 1831) used the term for investigating consciousness although he did not agree with Kant's dualism.

Three key figures in the development of phenomenology are Brentano, Husserl and Heidegger.

Franz Brentano (1838-1917) a psychological philosopher, developed the theme of intentionality which was an ancient concept derived from Aristotle. The main premise of intentionality suggests that consciousness is always directed towards an object. Du Preez describes (1991:30) this,

'to be conscious is to always be conscious of something. Consciousness is never empty. Consciousness is always being filled with its objects, as we see from such statements as 'I see John'; 'I hope to win the race'; 'I believe in God'. Each of these statements links a subject and an object. The object and the subject are bound in one reality, that of the intention' .

Brentano's re-establishment of this concept influenced his students including Edmund Husserl (1859-1938), and Sigmund Freud (1856-1939). Freud developed psychoanalysis as intentional systems of different parts of the personality (du Preez 1991) and Husserl, his reductionist phenomenological philosophy.

Husserl (1859-1938) is accredited as being the founder of phenomenology. He did not consider natural science was a useful way forward when wishing to investigate little known phenomena or human experiences. He identified the starting points were different. He suggested with human experiences one needs to begin inductively rather than deductively. In order to understand human beings, it requires interpretation and understanding rather than external observation and explanation as used in natural science (Emden 1991). Husserl considered the concept of consciousness, as experienced by an individual, was the only true reality and that no other reality could exist (transcendental phenomenology). He considered that as consciousness was the only real thing to exist, it cannot be thought away, whereas other objects can. This line was consistent to the subject-object notion, that a subject experiences his objective world through his senses.

Husserl was particularly interested in the analysis of a conscious act in order to arrive at essences of a phenomenon. Although trained in mathematics, he strove to lift philosophy to the level of a rigorous science through his phenomenology.

He stated that 'true phenomenology, is not a science of facts, but....of essential being......which aims exclusively at establishing 'knowledge of essences'' (Cooper 1990:40). Phenomenological reduction was his process of achieving this aim.

Cohen (1987:32) states that phenomenological reduction can occur in two ways: the first is described as 'the reduction from particular facts to general essences' and involves suspending consciousness of things and objects (eidetic or bracketing). The second involves suspending one's judgements, attitudes, beliefs and suppositions, (epoche, Greek for suspension of belief). This two stage reduction process allows one to return to the 'original intuition of things' (Kocklemans 1967), to appreciate the original essence of a phenomenon. Walters (1995) however, considers phenomenological reduction, epoche and bracketing as synonymous for a change in attitude necessary for rigorous philosophical enquiry.

The significance of such 'belief suspension' in a practical situation can be illustrated in caring; if descriptions of caring from people's experiences are gained and then reduced they should reveal the essence of caring, the original intention of the consciousness of caring. The researcher gathering such descriptions should suspend their own experiences, beliefs and prejudices of caring for the process to be rigorous.

The Husserlian approach remains in the Cartesian tradition of a subject-object differentiation (Outhwaite 1985). The metaphors of bracketing and epoche seem challenging demands of a human being and rather unrealistic if one holds to the assumption that one is 'situated', whereby understanding and interpretation develops from one's perspective, history, culture and experiences. In a previous study adopting a Husserlian stance (Clarke 1991), I as the researcher lived the difficulties in attempting epoche and bracketing. Through declaring my assumptions and meanings of the phenomenon under investigation I tried to suspend them from influencing the study. This did not feel a natural or achievable state to adopt and I question its potential for success. Husserl's approach was criticised and a further stance offered by his pupil Martin Heidegger (1889-1976).

Heidegger rejected Husserl's phenomenology, in particular Husserl's Cartesian conceptualisation of people as detached subjects existing in a world of objects. Heidegger rejected Husserlian metaphors of bracketing, epoche and intentionality.

Heidegger rejected Husserl's claim that one can let the facts speak for themselves, that essences, knowledge, are independent of interpretation (Walters 1995).

Heidegger, (1889-1976) argued that the understanding of a person cannot occur in isolation from the person's world. He therefore re-interpreted phenomenology to be existential and hermeneutic (Being-in-the-world and interpretive). His aim was to reveal the meaning of Being, acknowledging there is no such thing as uninterpreted experiences. Heidegger therefore adopted an ontological focus rather than Husserl's epistemological focus. Ontological questions are more concerned with 'the study of nature and the existence and of coming to be' (Teichman and Evans 1991:2). Husserlian and Heideggerian phenomenology are therefore different to each other.

Heidegger (1962) introduced the notion of 'Daesin' as an explanation of human existence and being, attachment to the world and hence the concept of person-hood. Leonard (1994:45) discusses Heidegger's view of a person as 'Daesin' in five main points;

- The person as having a world
- The person as a Being for whom things have significance and value
- The person as self-interpreting
- The person as embodiment
- The person in time

The person as having a world

World is considered in this context as the 'meaningful set of relationships, practices, and language that we have by virtue of being born into a culture' (Leonard 1994:46). The person then interacts to make sense of their world and capitalise on its possibilities. Heidegger refers to 'throwness' as the person being situated in the world from the moment of birth, through which, the person is influenced. This belief is contrary to the thinking that people can adopt an autonomous, disengaged stance to the world. As Heidegger argues there is no sense of detachment or objectification of the world as who one is, is affected by the world one experiences and the interpretations one makes towards it; 'World is both constituted by and constitutive of the self' (Leonard 1994:46).

However we often take our worlds for granted, and are unreflective, that is until the world we know breaks down which then promotes a more reflective, questioning mode.

The person as a Being for whom things have significance and value

People act in the world according to their situation and context rather than in any uniform consistent manner. Things have significance for each individual and these things may change within different contexts to reveal a different type of understanding. In the case of a person newly diagnosed with MND, she or he may have taken health for granted and in terms of life choices, lived with the premise there is plenty of time. However, with MND, time is a premium and previous interests such as work and career progression may become insignificant next to time with loved ones. This significant dynamic is important for professionals to appreciate as it can determine client needs.

The person as self-interpreting

Our cultural and linguistic heritage influences our self and our ways of interpreting our worlds that we are 'thrown' into. The significance of this is how nothing can be interpreted free from our own culture, language and background understanding. Every encounter is interpreted through our understanding in our inherited backgrounds.

The person as embodiment

In English, body generally means the physical object. In German and French, different words distinguish between the body which one lives and the body which one encounters. This has led English speakers to refer to the 'lived experience' and 'lived body' to capture these meanings. In terms of the lived body Emden (1993:19) explains,

'The lived-body then becomes the centre for all experience, the source of all motivation for action; the means by which consciousness experiences the world... and the avenue to awareness of others as embodied consciousness'.

This explains the concept of embodiment, experiences and meanings held within the body, not just the mind. Stewart & Mickunas (1974) suggest to further clarify this approach that, 'the body cannot even be considered apart from the perspective offered by the body. Perception is not a separation from an object being perceived, but is continuous, as the real world is the perceived world. In natural science terms this would not do, in human science terms this is the reality' (cited in Emden 1993:18).

The person in time

Heidegger associated his phenomenological view of the person with time as he suggested the horizon of being is time: as people move through life they are 'being' through time. One's history has an important bearing on one's understanding. Appreciation of one's past history is inevitable as it impacts on one's present and future being in time. Gelven (1989) summarises Heidegger's coherence of time as when all three domains are in harmony. In MND, the present and the future are out of balance and this presents problems to sufferers and their lay carers.

Heidegger's contribution to phenomenology transformed it from Husserl's transcendental approach to an existential/ interpretive or hermeneutic approach. Hermeneutics was his approach for analysis of being-in-the-world with the recognition that interpretation is universal for all understanding and presupposes prior understanding and that it is only possible to interpret according to one's own lived experiences. Heidegger used the metaphor of forestructure to explain that one's past experiences and beliefs cannot be denied in interpretation. In research terms therefore, the researcher is also involved and should declare their involvement rather than falsely bracket themselves out or attempt Husserl's 'epoche'. Indeed Heidegger stated it is not possible to bracket one's being-in-the-world (Walters 1995) and therefore it denotes the necessity for the researcher to continually reflect on their involvement and possible changing perspective.

Heidegger identifies the importance of dialogue in understanding which is required between current understanding and new concepts that emerge from enquiry. Dialogue with participants is important in the overall interpretation process with the awareness that any interpretation is always tentative and not an absolute or truth. In addition, any findings are presented for readers to make their own interpretations.

In summary, significant aspects of Heidegger's philosophy of phenomenology for use in this study have been identified as being-in-the-world (which rejects Cartesian dualism), his five ideas on personhood (Daesin), the concept of forestructure, the involvement of the researcher in interpretive work (which is contrary to Husserl's epoche and bracketing in phenomenological reduction), and the significance of dialogue, history and the hermeneutic circle. These areas are clarified in section 3.4.1. as Gadamer drew upon them to inform his hermeneutic processes.

Three emerging schools of phenomenological research reflect the contributions of Husserl and Heidegger. All aim to gain knowledge about phenomenon. The Duquesne school is attributed to Husserl, which strives for description of phenomenon through reduction and bracketing, sustaining the subject-object divide. Protagonists of developing analysis processes for this school are Van Kaam (1966), Giorgio (1970) and Colaizzi (1978). The Interpretative school is supportive of Heideggerian hermeneutic phenomenology where the focus is on what it means to be a person. Benner (1984), Benner and Wrubel (1989), Diekelman, Allen and Tanner (1989) claim this route for their interpretative frameworks. The third school is the Dutch school that combines the Husserlian and Heideggerian routes and results in description and interpretation. Here the main focus lies with Van Manen (1990)

3.4. THE HERMENEUTIC TRADITION

Heidegger used hermeneutics to support his phenomenology although interestingly the term and practice of hermeneutic interpretation are older than phenomenology. Indeed Ricoeur states the hermeneutic problem arose long before Husserl's phenomenology and he speaks of a grafting of the two, 'and, properly, must even say a late grafting' (Bleicher 1980:236). It is helpful to our understanding to trace its historical development before locating its usefulness to the study.

The term hermeneutic has been used since the eighteenth century to refer to the interpretation of texts (Outhwaite 1987). The etymology of the term arises from Hermes, the Greek mythical messenger of the gods. In order to deliver the messages, Hermes had to be conversant with the modes of expression and language used by the gods as well as the idiom of the mortals for whom the message was destined.

Hermes had to understand and interpret the messages of the gods, before he translated, expressed and explained the meaning to the mortals (Mueller -Vollmer 1985). Aristotle used the term hermeneutic for one of his texts in 'which he dealt with the logic of statements: the grammatical structure by which subject and predicate are united in human speech to reveal the character of things' (Mueller-Vollmer 1985:1) This emphasis on language remains an important feature in Gadamerian (1976) hermeneutics.

Following textual interpretation of the Greeks, the Reformation was the next most significant point in the hermeneutic tradition, when there was an attack on the Church's authority. Flacius, a Lutherian minister, suggested the Bible could be understood in its own terms as the word of God rather than those of the Catholic doctrine. Flacius claimed, 'that Biblical interpretation necessarily moved in a circle, that its individual books and passages were to be understood in terms of the meaning of the whole, while the understanding of the whole was to be achieved in light of an understanding of these individual parts' (Warnke 1987:5). We can appreciate how the German philosopher and historian Dilthey (1833-1911) accredits Flacius with the metaphor of the hermeneutic circle, also an appreciation of requiring interpretive rules to seek the meaning of a text.

Schliermacher (1768-1834) was a major figure in hermeneutics during the 19th century. He asked the question of how meaning could be comprehended and what methods would permit an objective understanding of the Bible and other texts and utterances. Dilthey furthered these questions and this firmly entrenched hermeneutics into a search for methods to objectify interpretation. Dilthey acknowledged the importance of historical circumstances and their effects on interpretation. He also suggested that understanding was the foundation of the human sciences through distinguishing between the sciences of nature and the sciences of the mind.

It is not the intention of this study to enter into the philosophical debate of Gadamer's concerns, only to appreciate that the natural science initiative of developing a methodology for research purposes did not sit comfortably with Gadamer. He was more interested in the nature of understanding (Hekman 1980). What is significant to this thesis is appreciation of Gadamer's contribution to hermeneutics, as he was influenced by Heidegger's work which locates the important contribution of both the phenomenological and hermeneutic tradition to the theoretical underpinning of this study.

3.4.1. Gadamerian Philosophical Hermeneutics and the Study

Hans-Georg Gadamer in his seminal text 'Truth and Method' (Gadamer 1975), clearly denied any intention of developing a methodology for enquiry, as he believed understanding is the hermeneutic experience and understanding, or verstehen, is more than a method, 'it is the way in which we get access to social reality in the first place' (Outhwaite 1985:29). Two central principles in his hermeneutics are the universality and historicity of understanding which can be traced to Heidegger's thinking.

Universality

Heidegger (1967) suggested hermeneutics is a universal 'because understanding is the fundamental way in which human beings participate in the world' (Outhwaite 1987:62). The importance of language is Gadamer's contribution to universality. This does not locate a general methodology for the human sciences but recognises a 'fundamental dimension of all human consciousness [as it] is expressed in language....Being that can be understood is language' (Outhwaite 1985:26). Use of language is always an attempt to share common meaning. Heidegger believes 'Language is the house of being', to which Gadamer adds, 'Being is brought to language...Being comes out of language by opening itself up' (Bleicher 1980:115). Gadamer appears to make no mention of non-verbal language which is considered a detriment to his thinking. In the context of this study, language was more than the spoken word. Some MND participants had tremendous constraints to their voices, but through being inclusive of additional approaches such as non-verbal techniques, it enabled messages to be sent.

Historicity

Gadamer accuses natural science of ignoring historicity when there is an importance of incorporating historical notions from experience into knowledge. Bleicher (1980:113) reports that 'a new experience does not merely imply the overthrow of an earlier one but represents a new and higher state of knowledge which comprehends both the new insight and an awareness of what had wrongly been regarded previously as a matter of fact: we now not only know more, but we know better'.

This sense of experiential learning requires reflective insight and consideration but is also linked to the hermeneutic circle where an individual's experience and learning can only be gained through the significance of the world in which one is enjoying the experiences and learning. In terms of helping to gain understanding of people's experiences, as in the new experience of living with motor neurone disease, this should also mean people know more and know better. Not just the affected individuals, but through giving their voice and experience to others, others should also know more and know better.

Gadamer, building on Heidegger's work, developed four metaphors to further clarify the hermeneutic experience; the hermeneutic circle, fusion of horizons, dialogue and prejudice. These are all applied to this study and therefore require explanation.

Hermeneutic circle

The hermeneutic circle presupposes there is pre-understanding which is bought to bear on all understanding, it is the background of life, experiences from being-in-the-world which one uses to make sense of the world and situations in the world. The hermeneutic circle is not conceived as a formal circle but as a concept to clarify understanding as involving a historicity and a being-in-the-world. In terms of research, appreciation of the hermeneutic circle recognises that all participants in the study have previous knowledge and experience, including the researcher. All participate in evidence generation because the hermeneutic circle cannot be avoided.

Indeed as Koch (1995:832) states 'understanding is not the result of a correct procedure: rather it is found in the hermeneutic circle'. This led the researcher to recognise that there can be no such thing as un-interpreted conversations, transcripts and observations.

Fusion of horizons

Fusion of horizons (perspectives) envelops historicity whereby the perspective of the researcher and the perspective of the researched are bought to bear on the project. The reader (as interpreter) will also engage with the project with their own horizons. The hermeneutic process is a dialectic in which two horizons can be fused together (Outhwaite 1987).

Gadamer considered the concept of horizon to be the range of vision that includes everything that can be seen from a particular vantage point (Hekman 1986). Individuals already have an horizon in order to understand another, as understanding is always from a certain perspective. The aim of this research is for the interpreter to consider perspectives of three different groups (not forgetting the interpretation arises from the researchers initial horizon), to find out where perspectives meet or diverge. This understanding could be actualised through locating themes which become evident through the stories with the researcher being clear regarding her own prejudices through reflection, and then validating these interpretations with the participants.

Dialogue

Dialogue is one of the basic tenets of philosophical hermeneutics. As Koch (1994:977) explains it is 'the dialogue which takes place between the researcher and text, or reader and interpretations, acknowledging that the researcher and reader bring to the analysis her or her own preconception'.

Four stages of dialogue take place in the research study. The first is between researcher and participant to generate the text. The second is between the researcher and the text (and participant and text) when interpretations are made whilst reflecting on one's own prejudices and the third is between the researcher and participant when seeking a fusion of horizons from the presented interpretations. Once the interpretations are reported, then a further opportunity for dialogue is created, that is for the reader and the interpreted text.

Prejudice

In light of the hermeneutic principles of universality, historicity and language, Gadamer denies that the researcher can gain understanding of the experiences and practice of other human beings in an objective, value free way. He believes the interaction of the researcher's beliefs and the informants' beliefs in research actually forms the understanding; any interpretation therefore cannot therefore be objective to the researcher, all understanding is situated. He revived Heidegger's concept of forestructure and developed it into his concept of prejudice.

Hekman (1980:101) reports the concept of prejudice as the 'cornerstone' of Gadamer's theory of hermeneutics. Gadamer believed our historicity, preconceptions and prejudices makes understanding possible in the first place (Outhwaite 1985). Prejudice or bias is an anathema to positivist methodologies but Thompson (1990) clarifies Gadamer's concept of prejudice recognising that researchers have an established background of pre-understanding which Gadamer refers to as prejudice, - it is the precondition of truth, not an obstacle to it.

Gadamer sees a positive possibility of prejudice as it encourages one to examine their prejudices. Hidden prejudices are a tyranny and 'one of the greatest impediments to understanding' (Gadamer 1975:239). Prejudice needs disclosure, although this process is not the same as Husserlian bracketing or epoche but rather a realisation of one's prejudices and a declaration of them to appreciate the 'situatedness' of the interpretation.

3.4.2. Summary of research approach chosen

Heidegger's phenomenology and Gadamer's hermeneutics form the basis of the theoretical underpinning of this study. Gadamer was influenced by Heidegger's work and he incorporated two central Heideggerian principles into his hermeneutics; universality and historicity of understanding. In addition, four metaphors clarify the hermeneutic experience; the hermeneutic circle, fusion of horizons, dialogue and prejudice. These six elements serve as the theoretical justification for the approach adopted in this study and support the development of the data collection and analysis process.

3.5. DEVELOPING A DATA COLLECTION/ANALYSIS PROCESS

A range of analytical processes designed for phenomenological research have already been noted in the Duquense, Interpretive and Dutch schools of phenomenology (section 3.3.). The least developed area appears in the interpretive school, unsurprisingly considering Gadamer's influence. Indeed Hekman (1986) reminds us how Gadamer was not intending to develop a method for research. However, it is possible to identify an approach to collect and interpret evidence, through attending to his metaphors and being informed by Heideggerian phenomenological principles. This study does not claim to have developed a 'method' but rather to offer the supportive rationale and decision trail relating to the conduced processes.

Pragmatically there is the need to generate a text for analysis and for 'language' to constitute that text. To this aim Hekman (1986) suggests attending to Gadamer's three metaphors or principles (fusion of horizons, prejudice and dialogue, in relation to Heidegger's phenomenological notion of 'being in the world'). These principles, as portrayed in table 2, were drawn upon when developing the guided conversation schedules.

Table 2. Principles for developing guided conversation schedules

1. The need to understand the horizon of experience through the conversation and transcript; that is, what caring in the world of MND means to the participant.

2. How the interpreted themes fuse with the interpreters horizons

3. Use of dialectic to achieve fusions

Hekman's first point highlights the need for a separate guide for each group as each may have a different experience and perception of caring. (see appendices 3,4,5 for the three guided conversation schedules). Morse (1994) suggests data collection can begin by listening to the stories of the informants through asking one general question and expanding it with prompts and cues. This principle was actualised and it served to allowed the researcher to remain focused in and responsive to the world of the participant.

Her second point focuses on the researcher as interpreter, how the research influences the interpreter, how in analysis and interpretation the researcher may employ a different horizon of meaning about caring. This point reflects what the researcher may learn from the participant and what meaning is made of the learning.

In Hekman's third point, the use of a dialectic prompted the need for a second guided conversation. The second conversation allows the researcher to return to the participant to discuss which of the researcher's themes fused with the meanings of the participant. The concept of 'fusion' appears rather extreme. Fusion insinuates the melting together of two ideas whereas understanding and acceptance are probably more realistic. One cannot ever completely appreciate the experiences of another or always have the same point of view even though there can be acceptance, understanding and learning about each others horizon.

3.5.1. Framework For Analysis Of Evidence

The aim of analysis is to interpret the lived experiences of care and caring gained from the guided conversations. Interpretation of lived experiences is at the heart of communication and developing understanding in everyday life. Nursing, and arguably every professional care group, relies heavily on people telling their stories which facilitates interpretation and developments.

Interpretation is always influenced by the listener's pre-understanding and history (Gadamer 1975) which can have negative and positive effects. The negative effect can be a closed mind which precludes accepting variations to their own prejudices. They are then unable to accept any alternative view. The positive effect is its basis for understanding and the potential for fusion of horizons. As the teller is presenting their story, it emerges more than 'telling it as it is'. Even the 'teller' has made their own interpretation of experiences. It would be more accurate to label the story as 'telling it as understood and currently perceived'.

Applying this process to the practice of care, if the historical stance of the teller (patient) is unknown or their existential story ignored, then care may become professionally rather than client driven. Failure to appreciate the client's needs runs the risk of inappropriate care which may be both insensitive and wasteful of resources. Interpretation of stories is at the very heart of delivering and receiving care. The espoused ideology of professional care is 'holism' which should be open to all aspects of human need. This stance is the one that I have been 'thrown' into and is therefore my prejudice governing care practices.

I needed to be aware of my prejudices as they steered my decisions through the texts created from the pilot guided conversations. This process required much reflection and was rather challenging, first to recognise my prejudices and then to realise how they were influencing my decisions. This process confirmed how my involvement as the researcher was not context value free attempting an objective analysis of text but was influenced by my experience in addition to my interactions with the participants. Apart from drawing on the participants to support my interpretations I also drew on the two supervisors to offer a sense of confirmability that the interpretations were rigorous and meaningful to the original stories.

Weisheimer (1985 :184) suggests there is the situation of trying to find a 'common sense between the strange and familiar'. If I encountered stories or values that I was unsure about or were outside my own known prejudice then I needed to question these values and my prejudices to deepen my understanding. I could not dismiss the other horizon but had to consider it as Bleischer (1980:112-3) suggests that,

> 'the task consists, however, not in placing oneself within the latter, but in widening one's own horizon so that it can integrate the other'... 'the experience he makes in the course leads to a new understanding is a hermeneutic one and essentially different from the experience that underlies the formulation of scientific methods' .

This process is not a 'method' but an interpretive act. As previously stated there is no established interpretive approach for analysis in hermeneutic phenomenology so it has been necessary to develop a process to illustrate the researcher's interpretative journey. It is recognised that such a process is only useful for explanation rather than being able to capture all of its permutations.

There is an appropriate reluctance of phenomenological researchers, 'to focus too much on specific steps in research methods for fear that they will become reified as they have become in the natural sciences' (Hycner 1985:279). However, in the pursuit of transferability and trustworthiness (Guba and Lincoln 1989) it is justifiable to offer an iterative framework of analysis which maps the analysis process used with the evidence in this study. This process drew on the work of Van Manen (1990:99) who writes about 'interpretative insight' through reflection and writing. Although themes and categories are common tools familiar to many qualitative approaches, Van Manen (1990:79/88) describes these as 'a means to get at the notion we are addressing. Theme gives control and order to our research and writing...It allows us to make sense, be creative, insightful and offer disclosure of meaning'. Colaizzi (1978) also offered a useful starting point, as although his work is focused on Husserl's phenomenology, there is the common need to appreciate the participant's stories and begin examining the parts that make up the whole.

Gadamer's metaphors (prejudice, hermeneutic circle, dialogue and fusion of horizons) are important within an hermeneutic analysis process.

In particular the aspect of transaction between researcher and participant, where one's prejudices are considered central to the interpretive approach, rather than being ignored. Apart from my professional background, whilst in the research field I interacted with the participants, in their homes or place of work, enjoyed their hospitality, guided the conversations through questions and was guided by their responses and stories of their experiences. I was affected by them and their stories and they were affected through the telling of the stories and by me as the researcher. It was a situation of mutual care as information, emotion and humanity were shared.

3.5.2. Approach to Analysis of Evidence

The analysis process consists of five-stages. As stated, initially it draws on the influential work of two phenomenological analysts, Colaizzi (1978) and Van Manen (1990). Although these two contributors are from the Husserlian and Dutch schools, their influence was structural as explained in the previous section.

A: Hearing and Writing the Story
B: Hermeneutic Interpretation
C: Learning through dialogue
D: Thematic construction
E: Constructing the conceptual model of phenomenon

These five stages are explained below and are illustrated with evidence from the three groups of participants in chapters 5 to 8 with further supportive examples in appendices 6 to 13.

A: Hearing and Writing the Story

1. Read each transcript to engage with the story as told, the text (Colaizzi 1978, Van Manen 1990)

2. Write out the story as understood to gain a sense of whole before entering into detailed analysis

B: Hermeneutic Interpretation

1. Question what is being meant by the stories. Use ones prejudices to raise these questions from each individual text to offer some insight into questions of what is being meant? What matters, what is it like? What is being learnt about care/caring? (Van Manen 1990, Colaizzi 1978)

2. Search and extract significant statements from each individual text which offers insight into questions the researcher has of what is being meant? What matters, what is it like? What is being learnt about care/caring? What examples are being offered from their experiences which can identify their caring values?

3. Cluster these significant statements from each individual text to construct first level meaning themes (Van Manen 1990), as the researcher's interpretations of the participants' experiences.

C: Learning through dialogue

1. Return to each participant to present the interpreted themes for further dialogue (Is this what the experience is really like? This is what I understand you were meaning, what do you think?) This is a process to validate stories and open possibilities for fusion whilst allowing the move to the interpretation proper (Van Manen 1999:99).

D: Thematic construction

1. Establish the second level themes from each individual transcript by weaving in the first level themes from conversation one with those emerging from conversation 2 (the fused horizon)

2. Cluster similar themes from each group to form categories which represent commonalties of values expressed from their stories. Identify themes which do not fit categories (differences)

3. For each group cluster similar categories into major categories (Select exemplars from the original transcripts to illustrate the categories - transcripts re-examined and illustrations offered)

E: Constructing the conceptual model of phenomena

1. Compare major categories across the three groups (people with MND, lay carers, professional carers) for similarities and differences

2. Formulate conceptual framework of lay and professional values of care

3.6. ESTABLISHING RIGOUR

Establishing rigour in qualitative research requires the application of specific criteria (Guba and Lincoln 1989). Trustworthiness is a vital principle which this final section aspires to establish. A supporting feature is clarification of a decision trail as Koch (1994:976) argues that 'trustworthiness (rigour) of a study may be established if the reader is able to audit the events, influences and actions of the researcher'. Throughout this thesis therefore, there is an emphasis on clarifying the decision trail of the researcher. Readers who engage with the study will use their own horizons and prejudices to guide their interpretations of the presented evidence. The resulting themes, categories and recommendations may not be in complete harmony to those of the reader but they should be able to follow the researcher's path. Guba and Lincoln (1989) suggest application of four criteria to substantiate the nature of trustworthiness; credibility, transferability, dependability and confirmability.

Credibility

Credibility of the researcher and the participants must be explicit. In terms of the participants, they need to be identified and described accurately (within the bounds of confidentiality and anonymity) to validate their appropriateness as participants. This requirement is addressed in chapter 4.

In terms of the researcher, there is the need to describe and interpret their experience throughout the study. Reflexivity is required and a research journal is supportive to this process. The journal provides a stimulus and source of evidence to reflect upon as Bannister et al (1995) suggest reflexivity is acknowledging the central position of the researcher in the construction of knowledge. Gadamer's notion of prejudice is significant here, which itself can be illuminated through self-awareness and reflexivity. The researcher therefore maintained a reflective journey throughout the study and examples of its contribution in promoting these goals are offered in subsequent chapters.

Transferability

This is also known as 'fittingness' and refers to evaluating whether the findings can 'fit' into contexts separate to the study situation. In addition whether the reader considers the findings meaningful and applicable to their own experiences (Sandelowski 1986). The question to be posed therefore is, 'can the findings be generalisable to other situations apart from motor neurone disease?

To address this question there is a shift from researcher responsibility to researcher/reader responsibility. There are no resources for statistical inference as in quantitative research so Morse and Field (1995) suggests the researcher should clearly state the characteristics of the research participants and the settings from which they came (see chapter 4).

The reader of the research is left with the judgement of transferability. The researcher is responsible for providing the reader with sufficient information, 'to provide the data base that makes transferability judgements possible on the part of potential appliers' (Guba & Lincoln 1985:316).

This responsibility is discharged by leaving a clear decision trail, clarifying the methodological framework and offering all the reader would need to know to understand the findings. Specific knowledge gained from one group may resonate with another group and therefore have 'transferability'. Other terminal disease processes that cause immobility, speech difficulties with retained intellect could present similar experiences and values (see chapter 2).

Dependability

Sandelowski (1986) considers a study can be judged dependable if the decision trail is clear to others. Koch (1994:977) adds that 'leaving a decision trail entails discussing explicitly decisions taken about the theoretical, methodological and analytic choices throughout the study'. This chapter has contributed to this aim. Madison (1988, cited in Plager 1994:79) states nine principles for evaluation of phenomenological hermeneutics which are based on practical reason. They support the approach taken by Guba & Lincoln (1989) and are listed as coherence, comprehensiveness, penetration, thoroughness, appropriateness, contextuality, agreement, suggestiveness and potential.

Confirmability

A test question of this criterion is, 'Have we been told enough about the research not only to judge the adequacy of the process but also whether the findings flow from the evidence? (Robson 1993:406). In other words, 'Is the evidence gained linked to its claimed sources?' Guardians of confirmability in this study rest partly with the supervisors who have availed themselves of

- the raw evidence; tape recordings, field notes, documents
- the processed evidence; write ups, summaries
- the formation of the findings; themes, categories, codes, patterns, the final report
- the process of the study; design, strategies and procedures used
- early intentions of the study; original proposal, personal notes, intentions, expectations
- the development of the tools used; interview schedules, observation strategies

In addition, this report also offers evidence to support the confirmability of the findings through offering clear construction trails of the evidence with numerous exemplars and illustrations.

3.7. SUMMARY

This chapter has offered the reader insight into the choice and justification for the methodological approach adopted in this study. Heidegger's phenomenology and Gadamer's hermeneutics have been explained. Their principles and metaphors applied to the study have been clarified. The background to the process of analysis that has been developed for this study is charted. Issues of establishing rigour in the research have been addressed. The next stage is to illustrate the decision trail through clarifying how the study was organised, then proceeding to offer the evidence, analysis and findings.

CHAPTER 4: ORGANISING THE MAIN STUDY

4.1. INTRODUCTION

The importance of a clear decision trail has been stated in chapter three. This chapter reports on the iterative process of organising the study. It captures the dynamics of the journey's beginning up to the point of collecting evidence. The chapter has four sections. First, particular attention is given to biomedical ethical considerations governing the conduct of the study. Second, it presents a discussion of the pilot investigation with its developmental effect on the main study. Third, access to and details of the sample in the main study are clarified. Fourth, the protocol and the collection of evidence are explained.

4.2. IMPORTANCE OF BIOMEDICAL ETHICAL CONSIDERATIONS

Ethical committee approval is a vital starting point for any research study. However, the on-going practices within a study determine its ethical conduct. This conduct needs to be transparent and informed by ethical principles. Four ethical issues are addressed as they were central to the study for avoidance of errors of judgement. These are securing informed consent, the right of refusal to join the study and facilitating leaving the study, protection of anonymity and finally reduction of participant risk, stress and vulnerability.

4.2.1. Ethical committee approval

A public starting point and a requirement for registration of a higher research degree involving human subjects, is to present the proposed study to a local research ethics committee. This permits a body of lay and professional people to scrutinise and question the potential benefits that may arise from the project in addition to its stated ethical conduct concerning the rights and protection of human participants. Ethical approval was granted for the study to commence by the Joint Ethics Committee at Southampton Health Committee in 1994.

4.2.2. Gaining informed consent

The vital action to protect subjects from harm is to obtain their voluntary consent (Beauchamp and Childress, 1989). Informed consent requires that each participant must know why the research is being conducted, their contribution in terms of time and effort, the uses of the information they offer and how findings will be reported.

It is imperative that this information be offered to prepare all potential participants prior to their decision to enter the study. Four stages were identified to secure informed consent without coercion. The most vulnerable group was identified as the people with MND. They were contacted through the voluntary agency, the Motor Neurone Disease Association (MNDA). First a public declaration of the study's purpose was presented to a local meeting of the MNDA. Second, the public meeting was reported through an entry in their local newsletter. Identification of potential participants was supported by the MNDA voluntary visitor co-ordinator. Once she was informed about the study and entry criteria she discussed the project with individuals on my behalf prior to my gaining an invitation to their home for a preliminary meeting. Fourth, during this meeting, I was able to personally secure informed consent.

Individually I explained the purpose of the research, their potential contribution, the nature of the conversation and the use of their information. I negotiated the boundaries of my intrusion and offered the opportunity of declining involvement. A copy of the guided conversation sheet was issued and by creating a natural pause between the preliminary meeting and the first conversation, I allowed them to withdraw. This approach proved successful in the pilot investigations and was extended to the main study for the lay people.

Although I had prepared written consent forms, it became inappropriate to ask them to sign a form. This point also highlighted a physical deficit, they could not easily write. I made a decision in the field not to ask participants to sign this document. I appreciated how consent is continuous and dynamic. A signed piece of paper does not imply the current state of consent. Indeed a signed consent could pose a threat by being interpreted as a contract and so a potential coercive device to a participant. Instead I secured verbal consent on every visit which was recorded on tape.

Contact with the professional carers was made by telephone to explain the project and their participation requirements. A mutually convenient appointment was arranged for a personal meeting. Again, the potential participant could withdraw at any point. Again, an oral dynamic consent principle was adopted.

4.2.3. Right of refusal and facilitating leaving the study

It is important that there should be a 'no penalty' right for participants to withdraw. This right was tested in the main study. One MND participant, at the pre-arranged meeting for the first guided conversation, became very tearful as I was setting up the audio recorder. The conversation was suspended immediately. The researcher had to comfort the participant and establish a general conversation to calm the person. The prospect of talking about MND was just too painful and the issue was not pursued. The patient was protected from further distress and apologies were offered for the distress caused. The MND participant was immediately withdrawn from the study.

Another MND participant had completed the first guided conversation but declined to enter into the second after receiving her first transcript. Her refusal was reported by her lay carer who did continue in the study. On both of these occasions, it was imperative that the wishes of the participants were immediately respected. The responsibility on the researcher concerning the principle of non-maleficence, became very evident and required immediate action to reassure the participant that they would not be pressurised into being part of the study. In addition, one professional carer moved employment location after the first conversation, and declined further involvement.

4.2.4. Protection of anonymity

Protection of participants' anonymity proved quite challenging. Participants in the project talked with each other and informed each other of their involvement, particularly amongst the team of professional carers. Care was taken not to mention other participants and the reporting has not identified work places or other possible identification traces, in an effort to preserve anonymity.

Pseudonyms are used in the study and there is no clear identification of location beyond the study being focused in the South of England. Two branches of the MNDA co-operated with the study, and professionals from two health authorities and two social services authorities. Some participants wished various aspects of their lives to be remain unspecified to further protect their anonymity, for example, generalisation of their occupation descriptions.

4.2.5. Reduction of participant risk, stress and vulnerability

Research into people's lives can be a real threat and entry into a research project can expose people to risk and vulnerability. In this study the risk and vulnerability applied to both the participants and the researcher.

Sensitivity was necessary, to the possibilities of causing distress to people with MND and their lay carers. I appreciated I may be pushing people to the limits of their emotions in asking them to talk about their life threatening disease and how they were being cared for and caring for others. Indeed there were many occasions when tears were shared but they wished to continue. However, returning for the second meeting was like visiting a friend. I had to be aware of not over challenging the trust and openness they were offering me. I was constantly aware of the potential for harm.

I was concerned about the limits of my personal abilities being tested on two levels. Initially how I would cope with the emotions and reactions released from the participants. In addition, was the question would I know when to stop if a person became distressed which would require me to relinquish the research imperative?

I reflected on the two issues and established my own ground rules for these two possibilities. From the personal coping perspective, I made sure that before each meeting I had some personal space to prepare and think about where the participant may be located emotionally. When I had rehearsed broad possibilities I was receptive to their actual demeanour and able to adjust. Also I tried to ensure there was someone I could talk to after a meeting, not to disclose confidences, but to support me. This process was quite effective but on a couple of occasions I completed two guided conversations with only a short break. This was particularly difficult in terms of my emotions and energy reserves and I tried to avoid this situation.

On the second level, knowing how to cope with a person who may become distressed, the protocol four stage preparation helped me deal with this situation. There were tears, silences and distress in the conversations but if I tried to discontinue them the participants declined the offer and continued after a few moments.

The professional carers needed protection from risk, stress and vulnerability. They experienced lesser emotional incidents but they felt more vulnerable after the death of a patient. Initially we met in their place of work and I realised they had to carry on working after our meeting. I always tried to close the conversation and divert from the topic area to other general issues of mutual professional interest, prior to taking my leave.

4.3. PILOT INVESTIGATION

The starting point of the pilot study was to 'check out' the world of care, to become sensitive to the issues and to develop guided conversations with individuals.

4.3.1. The checking-out phase

The first place to start in the checking-out phase was personal. In my understanding of professional care, I reflected I had been mainly influenced by institutionalised care patterns following 12 years in hospital clinical practice. I appreciated the effects of institutionalisation on patients and clients, the power strategies and control implications of large institutions. I had also grown beyond these constraints as I had experienced many moments of personal engagement with patients and their relatives. I had identified with families in distress and been existentially close to many people in their suffering, as is common when most nurses recount their stories from practice. In addition, I had my personal experience of caring and being cared for through family and friends.

Although I had extensive experience in institutionalised health care settings with patients, the cared for, and professional carers, there was a deficit in my experience of community care and appreciation of lay caring. Such a world was relatively unknown to me so I began to investigate this deficit. I visited a local care association, a lay body charged with organising lay care for the public. During my visit to this association I met with it's executive officer.

This highlighted a growing 'business' of organised paid lay care to meet the needs of consumers. My impression of lay carers as lady 'do-gooders' was overturned through the new reality of a business orientated, cost containment approach. I discovered the lay carers in this organisation are invariably young people, many enrolled for the National Vocational Qualifications (NVQ) in Care.

In the world of motor neurone disease, I learnt how paid lay social carers play an important supporting role. They can offer companionship through their presence in addition to practical interventions such as helping with washing and dressing, shopping and cleaning. This group of carers would prove an additional fourth group worthy of study but inclusion of them would have made the study too large to be feasible. An awareness of their organisations however, offered valuable insight into their contribution. I wanted to concentrate on immediate unpaid lay carers, usually a relative or friend, as the continuing care person. In light of this I needed access to these people.

4.3.2. Access into the world of motor neurone disease

The principles for MND participant inclusion were for each person to be aware of their diagnosis, to be a consenting adult and able to communicate in some form. Two approaches were tried during the pilot study between March and June 1995. My institutionalised background initially led me to approach a hospital consultant.

a) Hospital consultants - traditional gatekeepers to patients

Hospital consultants have traditionally been the access channel to secure introductions to patients. They are a group of health care professionals who appear to identify almost an ownership claim to 'their' patients as they have control over key resources (Atkinson 1981).

In 1995, I visited a neurological consultant to discuss the proposed study and to gain consent for introductions to 'his' patients diagnosed with MND. Commencing my discussion with expectations of his interest and concern for people diagnosed with MND, led quickly to disappointment. The consultant's demeanour was cold, matter of fact and defensive. He talked at me in a superior way about MND. His concerns were an objective assessment of a disease process, the intricacies of securing a diagnosis and the realisation that his role thereafter was one of monitoring and controlling certain resources. My interpretations of his language and manner unravelled his value base I assessed as being objective, scientific, apparently lacking in understanding of the impact the diagnosis may have on sufferers and told with a sense of importance of his professional role. The stance of receiving this information, of being a patient and the possible effects of being told such a diagnosis did not enter the conversation. This shocked me and made me aware of our dissonance in prejudice, horizon and values. This discussion made me reconsider the route to gaining access to people with MND. Although he gave his permission to access to 'his' patients, three prejudices prevented me from pursuing this line.

1. If I introduced myself to a newly diagnosed patient from this medical/power source, I may be identified with that source which I wished to avoid.

2. My assumption was that that newly diagnosed patients would be frightened, distressed and emotional. From my experience of meeting with the consultant, there would be little understanding of these aspects and I did not wish to be associated with that stance.

3. There was the potential danger that a request from a consultant to enter a study could be interpreted as approaching vulnerable subjects who may consider the research to be linked to 'part of the treatment'. This might wrongfully influence their decision to participate.

In conclusion, I predicted this route was not coherent with the study's aims of offering people a voice of their experiences and to gain evidence concerning values of caring.

b) Access route through the MNDA

The alternative adopted approach was through the Motor Neurone Disease Association (MNDA). This voluntary organisation functions solely for the benefit of people with MND and their families. MNDA leaflets were in the neurological out-patients department and I was aware of their existence from my clinical experience. Not all people with MND join this organisation so I was aware I was automatically restricting the study to people who had joined. This may have limited the range of people available to enter the study but I was clear that non-participants members were invited into the study.

The MNDA is organised by and for the benefit and support of people with MND and their families. It has an executive body and central offices in Northampton and international links. The organisation is interested in supporting health care professionals with information about motor neurone disease and it funds research activities in cure and care strategies from charity campaigning. Details of the protocol employed through the MNDA have been explained in the ethical section of this chapter.

4.3.3. The pilot sample

The participants in the pilot investigation all had experience with MND. The study participants with MND fulfilled the criteria as outlined previously (see 4.3.2) The criteria for lay carers was as follows:

i) Consenting volunteer
ii) Aware of diagnosis of person(s) with MND
iii) Experience of caring for at least one person with MND

Criteria for professional carers to participate were as (i) and (ii) above plus

iii) A member of a care profession involved with a person with MND

The pilot sample involved three MND participants, three lay carers who were not related to the MND participants but had been bereaved within the previous year and one professional carer, a nurse working in a community young disabled unit.

MND participants

The people with MND included two men (aged 42 years and 70 years) and one woman (aged 72 years). All were members of the MNDA but only the woman was an active member. Both men were house bound and too disabled to attend meetings.

The elder man died in September 1995, about three months after we had met, the younger man died within six months and the woman within a year. Their deaths highlighted the emotional risk and vulnerability of the project.

I had developed sound relationships with them and their families through attending the MNDA meetings and in conversations in their homes. Their deaths also raised a methodological issue, a time constraint when wishing to return to participants at a later stage in the study for validation of my interpretations.

Lay carer participants

I met with three female lay carers. Two were in their 70's and one in her 50's. All had first hand experience of caring for someone with MND. Two women had both cared for their mothers. The third lay carer had cared for her husband. They offered their stories with dignity and detail but it was difficult to ascertain how their bereavement was affecting their stories. This concern led to the pre-qualification that lay carers should actively be caring for a person with MND at the point of inclusion in the main study.

Professional carer participant

At the pilot stage in the study it was anticipated to invite only nurses into the professional carer group. Access was to be pursued through a community hospital for the young disabled. A nurse from this community hospital was invited to join the pilot investigation. However, I soon learnt from all three groups of participants that examining one professional would be constraining to appreciation of the MND experience.

4.3.4. The pilot conversations

MND participants

Two meetings were held, first in the company of the MNDA voluntary visitor during which I left a conversation guide. The second visit was unaccompanied when I had one pilot conversation in their home. I did not conduct a third meeting at this stage but learnt that it would have been useful and so incorporated it into the main study. Two participants were very vocal and able to speak clearly and comprehensively. They did not shy away from any of the issues and although there were some moments of reflection and emotion which were challenging to everyone, they were determined to tell their story. The third participant had a bulbar weakness and as such this conversation was challenging.

Through careful listening, repeating his sentences for confirmation and really 'tuning in', we learnt to manage. It was personally a stressful experience seeing people so disabled and very taxing to communicate with them to steer a conversation into such a sensitive and painful terrain.

The partners of the three participants stayed with them during the conversation and although at times this added to the richness of the stories, I considered it did not allow the people with MND to always feel free to speak for themselves. In the main study I met with them alone.

The meetings were a great privilege and I realised how eager they were to tell me their stories, how honest their stories were and how the style of their telling told me much about their values related to being cared whilst caring for others. I also realised that three types of stories emerged inside the story of care; their emotional aspects (reactions to the disease/death), their physical aspects (coping with deterioration) and their meaning aspects (making sense of the disease/future death).

Lay carers participants

Although I had met lay carers whilst with people with MND, I additionally met three lay carers who had been bereaved. I met two in their own homes and one visited me, at her request. They offered their experiences of learning about the disease, how their practical interventions grew as their relative's physical abilities deteriorated. They had been emotionally and physically stressed through their caring but also tried to find some meaning in the situation.

It was a unique experience for me hearing stories from lay carers. I had experience with patients but had never before talked at length with relatives. I was able to realise the incredible work they had contributed and emotional stress they had endured.

Professional carer participant

The one professional carer in the pilot was a nurse which limited the scope. I realised that caring for a person with MND involved a multi-disciplinary team of professional carers.

Therefore, to gain insight into the delivery of care to people with MND in the main study, it would be more realistic to gather stories from a group of professional carers.

4.3.5. Tentative themes from the pilot conversations

It was not the intention to complete a full analysis of the evidence gained from the seven participants in the pilot investigation but the learning I gained from this experience influenced my perspectives and therefore favours inclusion. The analysis process at this stage was embryonic and cannot claim to be fully influenced by the principles and metaphors of phenomenology and hermeneutics. However, through identifying phrases of significance about caring from each of the transcripts and collating these statements, the following 'themes' emerged. They are presented here with the intention of helping to set the scene and illustrate their influence, they do not formally contribute to the main findings.

Pilot themes from MND participants

Uncertainty of the problem - the long trail to a diagnosis
The telling - an unpleasant experience
Inevitable physical deterioration
In the chair - immobility
Frustrations of change
Improvisations of lay carer
Need for team support

Pilot themes from Lay Carers

Shock of the reality ahead
The awful telling
Importance of humour
Search for hope
Thinking of their future alone

Pilot themes from Professional Carer

Need for continuity of personal care
Frustration of the cared for
Time investment
Aware their senses heightened from physical deterioration
Difficult to build up trust with patients
Need for humour
Empathy for lay carer
Tension with facilitating their independence
Need for a co-ordinated approach to care

The themes were not taken to the participants for a second conversation nor were they developed into categories. However, the presence of identifiable themes encouraged the researcher that there was much to learn about caring in motor neurone disease from the three groups. It reaffirmed that the project was worthwhile and that an evidence based study into motor neurone disease was well received by the participants.

4.3.6. Seven learning outcomes gained from the pilot investigation

The pilot investigation helped me in two dimensions, first to engage in and learn about experiences in the world of motor neurone disease and second to further shape the design for the research study. Seven aspects contributed to refining the main research study.

1. Access to people with MND and lay carers was possible through the MNDA

2. Cascading access to the main sample should start with the MND participants. They could then identify their main lay carer and their professional carers. This order would ensure the enquiry remained focused around the patient.

3. The pilot investigation allowed the conversation guide to be refined and a protocol developed for the conduct of the guided conversations

4. Meeting with each participant individually was preferable as it would allow them freedom to tell their own story

5. No longer than 3 months between the two guided conversations should lapse with the MND participants, due to the threat of death

6. Recognition that the guided conversations were distressing for them and myself and support needed to be in place

7. Communicating when a person has speech difficulties is possible. Repeating their words for their confirmation of my understanding and using the audio tape to record these words with notes taken of gestures being used.

4.4. MAIN STUDY ACCESS TO PARTICIPANTS

The majority of the fieldwork for the main study took 13 months between May 1996 and June 1997, although further evidence was collected in September 1997. During the first guided conversations, meetings took place with six patients, six lay carers and nine professional carers. In September 1997, a further three professional carers were included into the study. The following section details the process for collection of evidence.

4.4.1. Access to MND participants and their Lay Carers

The route of access to people with MND and their lay carers took place through two branches of the MNDA on the South Coast of England.

4.4.2. Criteria for entry into the main study - MND/LC participants

The criteria for entry into the main study built on that developed for the pilot investigation as follows:

i) A firm, known medical diagnosis of MND
ii) Consenting volunteer
iii) Able to communicate their experiences of living with MND,
iv) Ability and willingness to participate in two conversations with the researcher, each of about an hour's duration and to read through a transcription of the first conversation for verification of accuracy.

I began meeting volunteers for the main study in May 1996. I asked them to identify their most significant lay carer. All but one person identified their spouse and these five lay carers agreed to be included in the study. A sixth lay carer was also included in the study even though his spouse declined to participate. The conversations from people in these two groupings (n=12) was completed in January 1997, before entering the world of the professional carers.

4.4.3. Access to Professional Carers

A strategy for access to this group was untested in the pilot study although a multi-disciplinary group was desired. The purpose was to gain an understanding of professional caring values which people with MND and their lay carers experienced. Espoused values of caring were not sought but rather their values in use which could be substantiated by the evidence already gained from people with MND and their lay carers. Evidence of 'good caring practice' was desired to appreciate the values needed by the cared for in its delivery. The people in the best position to judge 'good caring practice' were considered to be the clients.

As content saturation was reached with six MND and lay carer participants, the same number was predicted for care professionals. However, a multidisciplinary team of nine practitioners was secured through listening to the judgements of a MND participant and his wife who identified their team as one offering good practice. I reflected on the stories I had already been privileged to hear. Their stories concerning their experiences with professional carers had been mixed in terms of what they perceived to be 'good' or not so 'good'. However, this one couple stood out as having separately reported experiencing 'good' caring from their team of care professionals. This couple gave their permission for me to contact their nine professional carers to invite them into the study. This team consisted of the following health care professionals in order as presented by the couple; Nurse Specialist in Community Rehabilitation Service, General Practitioner, District Nurse, Physiotherapist, Speech and Language Therapist, Social Worker, Occupational Therapist, Dietician and Neurological Consultant.

I contacted them individually by telephone, to ascertain if they were willing to participate in the study.

I did not make requests through their managers for permission but left the decision solely with the professional. I explained who I was, how I had received their name, the intentions of the study and assurance of an ethical approval. Six health care professionals agreed immediately to join the study, three asked to telephone me back when they had themselves asked the MND/LC couple permission to participate. All nine professional carers met for the first conversation. Eight were able to meet for the second conversation. I began collecting evidence from the professional carers in January 1997 and completed both guided conversations by June 1997.

4.5. PROFILES OF THE THREE GROUPS IN THE SAMPLE

The sample obtained can be described as a purposeful sample (May 1993) in that all participants were in the world of caring in relation to motor neurone disease. They all met the criteria for inclusion in the study. The three groups are considered in turn to locate their characteristics.

4.5.1. The Cared For

The time since diagnosis to the first research conversation was between three and a half years (MND 4) and six months (MND 5). This may have had an effect on their coming to terms with the disease and their coping strategies although this aspect was not explicitly pursued in the conversations.

The youngest was a woman of 38 years. The joint eldest both 69 years of age. There were two women and four men in the sample. To ascertain how typical the sample group with MND was, it is useful to consider the types, age and incidence of MND.

Table 3. Profile of Cared For - MND patients

	Sex	Age	Relationship to lay carer in study	Occupation of cared for	Date of Diagnosis
MND1	Male	69	Husband	Retired from Telecommunications	April 1995
MND2	Female	49	No relation	Hairdresser	November 1994
MND3	Male	40	Husband	Council Employee	September 1995
MND4	Female	38	Wife	Secretary	October 1992
MND5	Female	69	Wife	Housewife	March 1996
MND6	Female	54	Wife	Health care professional	September 1995

There are three main types of presentation in motor neurone disease as follows: amyotrophic lateral sclerosis (ALS), progressive muscular atrophy (PMA) and progressive bulbar palsy (PBP). There is considerable overlap between these forms of MND although the origin of the symptoms is usually an indicator of the initial form. Although the participants did not identify their type of MND, it is possible to ascertain this by onset of symptoms.

ALS is the most common, accounting for about two-third of cases. It is reported by the MNDA (1994) that men are more affected than women in the ratio of 3:2 and it is more commonly found in people over the age of 50. Symptoms usually begin in the hands or feet with people noticing a tendency to trip up or to drop things. This type fitted the presentation of MND 2, (49 year old female), MND 3 (40 year old male) and MND 5 (69 year old female) which from the description above, could be seen as an atypical sample in terms of age and gender.

PMA affects only 7.5% of patients (MNDA 1994), five times as many men as women and usually presents before the age of 50. Its presentation is muscle wasting in the hands and is a slower progression than the other forms. No person in the sample fitted the presentation of this type. However, with PBP, symptoms begin with speech and swallowing problems and is slightly more common in women than men, and in older people. Those who presented with speech problems first included MND 1 (69 year male), MND 4, (38 year old female) and MND 6, (54 year old female). This group fit the typical statistical offerings in terms of gender but not age.

They all identified their marriage partner as their main lay carer except MND 2. She was a married woman whose husband was living in the marital home but they had a difficult relationship, both before and during her diagnosis. The husband assisted with limited care and did not wish to be included in the study. She had various social services care attendants assisting her at home and could not readily identify a 'main' carer.

The MND participants were all members of the MNDA but only those identified as MND 1 - 3 actually attended any of their local branch meetings. The other three people stated they did not attend as they did not want to see other people with MND but were receptive to the MNDA voluntary visitors. All participated in two guided conversations apart from MND 4 and MND 5. The former refused to participate in the second interview as her speech deteriorated. MND 5 died suddenly and unexpectedly, before the second meeting.

4.5.2. The Lay Carers

The lay carers all participated in two guided conversations with the researcher. In tandem with the MND participants, their experience as lay carers ranged from three and a half years to six months. Although this factor was not explicitly pursued, it does not mean that the length of their experience did not influence their caring values. However, the time interval between the guided conversations does identify some changes in their attitudes, particularly when they knew their relative was nearer death as they then began looking ahead more for themselves.

Table 4. Profile of Lay Carers

	Sex	**Age**	**Relationship to MND**	**Occupation of lay carer**
LC1	Female	60	Wife	School teacher
LC2*	Male	73	No relation	Retired industrial manager
LC3	Female	38	Wife	Part time dinner lady
LC4	Male	40	Husband	Architect
LC5	Male	73	Husband	Retired policeman
LC6	Male	55	Husband	Senior Civil Servant

The ages of the lay carers ranged from 38 years to 73 years. There are two women and four men in the sample of lay carers. All lay carers were identified as being the main lay carer by a person with MND. In the case of LC2 however, the person with MND declined to participate in the study at the time of the first scheduled guided conversation although her lay carer continued. Four of the lay carers were employed although the school teacher took reluctant early retirement due to her husband's ill health.

4.5.3 The Professional Carers

The nine professional carers had all participated in the care of MND3/LC3 and were identified by this couple. The professionals had had varying degrees of experience with caring for people with MND in the community.

Table 5. Profile of Professional Carers

	Sex	Occupation	Case experience
PC1	Female	Speech and Language Therapist	approx 5 cases
PC2	Female	Nurse Specialist, Disability	approx 3 cases
PC3	Female	District Nurse	First case
PC4	Female	Dietician	First case
PC5	Female	Social Worker	First case
PC6	Female	General Practitioner	First case
PC7	Female	Physiotherapist	Many cases >10
PC8	Male	Neurological Consultant	Multiple cases >100
PC9	Female	Occupational Therapist	Many cases >10

As can be seen from table 5, four of the professional carers had never participated in caring for people with MND before, only two professionals had been involved with up to 5 cases and two professionals with more than 10 cases. This situation was relevant in the level of experience they had about caring for a person with MND. It also demonstrates the sparse knowledge base about caring for people with MND in the community. The physiotherapist was considered a practising 'expert' she was often asked for advice and guidance on physical aspects of care together with predictions of disease trajectories. The neurological consultant had most experience with people with MND but this was focused on securing a diagnosis and six monthly out-patient clinics rather than continuing home care. Only one professional was male and apart from the dietician, they were all over 30 years of age.

4.5.4. Issue of difference in sample of professional carers

There is an issue of difference in sample structure for the professional carers compared to the other two groups. The MND and lay carers could be called two homogenous groups. Although 'professional' was a commonality for the third group, their distinct disciplines were not. This means the credibility of their evidence could be brought under question, as it had not been validated or 'saturated' by other members of their respective professions, despite this being internally achieved amongst the nine participants. Morse (1995:38) would label this as a 'validity/reliability gap' in terms of obtaining an 'adequate and appropriate sample', as only one member of each profession was represented. One approach to strengthen the credibility (validity) of the evidence was the second conversation when discussion took place concerning the first level themes. However, to further strengthen this situation other options needed consideration.

One option was to secure a group of professional experts to validate the evidence gained from each speciality. In practice, this would mean gaining a further 9 groups of professionals (if each group consisted 4 people this would mean n= 36) to discuss the evidence already secured from interviewing 9 professionals twice (n=17 transcripts, due to one attrition). My reservations about pursuing a further full scale sample were as follows:

i) if only the professional carers were subjected to this approach, the sample size would dramatically increase far in excess to the other two groups. This would create an imbalance. Already they had 9 voices in their one group in contrast to 12 voices combined across two groups.

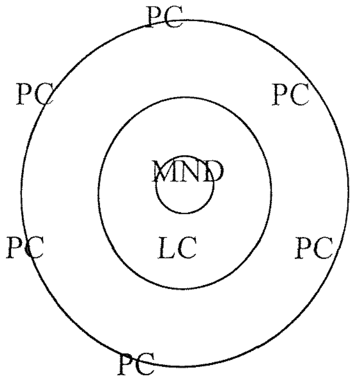
ii) the original focus of the study was to investigate values of care from the perspectives of three 'groups', not particular professional contributions. The common denominator between the three groups was that they were all in the world of motor neurone disease and had the relevant experience. Although the professionals are all individuals with different background experiences, so were the other two participant groups. The first level themes of caring values were evident, albeit with some similarities and differences, but this was consistent with the homogenous groups. For example; some professional carers wanted personal involvement with MND patients some did not; some lay carers wanted to help their spouse whereas others found a build up of resentment. Three options to approach this situation are worthy of consideration, to exemplify the tension, and the choice of action taken.

Option 1

This option would have consisted of six sets of 'cases' whereby there would be a person with MND at the centre, their identified lay carer (LC) and their professional carers (PC) in the set (Figure 2).

This approach would involve six people with MND, six lay carers and six teams of professional carers. The latter group could constitute nine individuals which if multiplied by six would lead to 54 professional carers. The balance of proportions per sample of participants would be far too loaded to capture caring values from a triad and so this option was rejected.

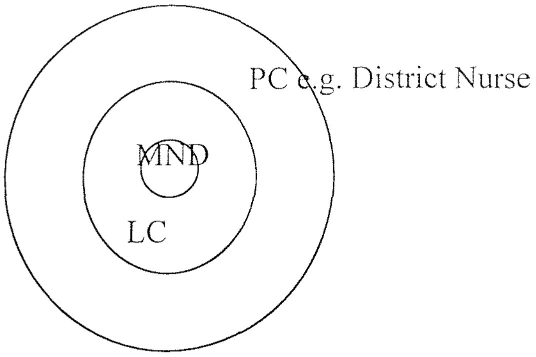
Figure 2. Option 1 sample: Six sets of MND/LC and Team of Professional Carers (PC's)



Option 2

This option would consist of six sets of the people with MND at the centre, their identified lay carer and one professional carer such as one district nurse. This situation could result in only one professional group being considered. This option was a potentially workable approach if it was desired for only one professional group to be included. This set would not reflect the reality of the situation experienced by people with MND who had to interact with many professional groups. This option would therefore not reflect the clients experiences.

Figure 3. Option 2 sample: Six sets of MND/LC and one type of PC for all six sets

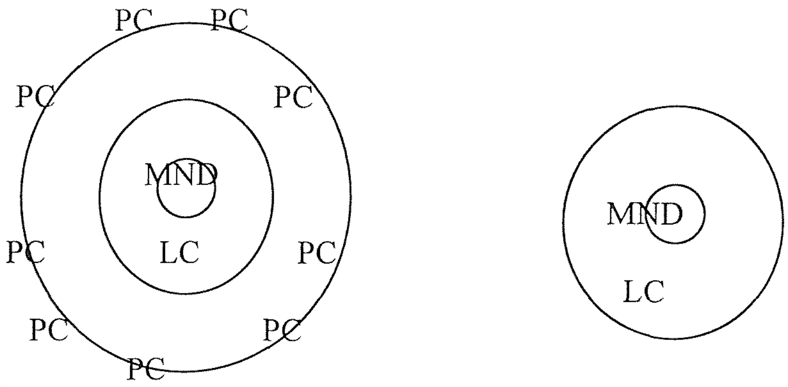


Option 3 - *the option adopted*

This option involved six sets of one person with MND and their lay carer with one of the six sets identifying their team of professional carers. The team identified would be one considered a 'good caring practice' team by the person with MND and their lay carer from their actual experience.

A true contrasting view could be observed if a 'not so good' team could have been identified and interviewed, this was not pursued.

Figure 4. Option 3 sample: One set of MND/LC and team of PC's with additional five sets of MND/LC



PC's as recorded in section 4.5.3.

This option however, takes us back to the original tension, are the professional carers a team or a collection of individuals? It can be argued that the six people with MND and the six lay carers offer sufficient supportive cross-critical evidence to validate each other to satisfy the issues of saturation and rigour. However, are the professional carers values typical or not?

Do their values need peer validation? Are the values portrayed supportive of their individuality as a person or as a separate profession?

There was no cross-validation of persons with MND. Each had their own story to tell so they could equally be considered a collection of individuals suffering a disease offering their own attributes for living and coping with the disease through their experience. There was no validation between one lay carer and other. Following this line of argument, the professional carers are nine individuals who collectively offer a professional perspective of caring values in the context of motor neurone disease towards one patient and her/his lay carer. There was no emphasis for matching their 'technical interventions' as their caring values were the focus of this study.

Option 3 was the adopted way forward but cognisant of the tension, further supportive action was taken to enhance the robustness of the 'professional' evidence. Expert groups of professional carers were sought to ratify the evidence gained from the individual professionals.

To maintain the cascading access principle of gaining the sample, I wrote to the eight remaining professional care participants. They were asked to identify 3-4 colleagues who could meet with me to verify the interpretations. Four professionals responded to my letter. Two of these responded in a negative sense. Another stated the name of one person who may be able to help, this was considered too small a sample to pursue. The consultant neurologist offered a list of six other names of consultants that I could approach. Four positive responses to participate were received but one was unable to meet in the immediate future. Three consultant neurologists were interviewed in October 1997 to critically cross-check the original evidence from the neurological consultant, this resulted in a congruent outcome. The evidence was shared with the two research supervisors.

This process had identified a shortage of people with experience in caring for people with MND in the geographical area of the study.
This sample saturation was evidence that no other professional carers had experience about MND, there was no other collective team. This does not mean such a team does not exist in other geographical areas but the patient catchment area (across two health authorities) had no such human resources to draw upon.

4.6. COLLECTION OF EVIDENCE IN THE MAIN STUDY

The goal of interpretative phenomenology is understanding the lived experiences. This requires the approach to evidence collection to be as naturalistic as possible so '*participants do not feel unduly awkward or constrained by the research interview or foreign, abstract* language' (Benner 1994:108). The main approach to collection of evidence was through the use of guided conversations (see chapter 3 for further explanation of the principles behind this decision). These guided conversations were designed to lead the participants into their story whilst guiding the focus to remain with the experience of caring. This section will clarify the approach taken through establishing the time frame and settings for the conversations, the protocol followed with the guided conversations themselves.

4.6.1. Time frame and settings of the guided conversations

Evidence was gained from the three groups over a 13 month period between May 1996 and June 1997. The cared for and lay carer evidence was collected between May 1996 and January 1997. The professional carer evidence was secured between February 1997 and June 1997.

Two guided conversations were conducted, each one lasting between 45 to 90 minutes. Longer conversations tended to be with the cared for, particularly those with speech difficulties. The first addressed the detail of their stories of living and caring in MND and the second was more about exchanging interpretations.

A total of 21 first conversations were conducted and 18 second conversations.
The reduced number of second conversations related to one MND death, one MND withdrawal and one PC withdrawal. This resulted in 39 transcribed conversations, a total of 920 pages of transcript gained over approximately 60 hours of guided conversations.
A further three hours of conversation were conducted with the additional neurological consultants. Further evidence was collected through field notes of the interactions with the participants, the researcher's reflective diary entries and visits made to local MNDA meetings. During the home visits to suffers and their lay carers there was the opportunity for direct observation and in some cases limited participation in care by the researcher.

The MND and lay carer participants elected to be met in their own homes. One exception was the second conversation with LC4, due to the fact that his wife (MND4) did not wish to participate in the second guided conversation we met at his work place. The professional carers were mostly interviewed at their work place, however, the physiotherapist invited me to her home.

4.6.2. Guided Conversation Protocols

Two protocols for the collection of evidence were based on the pilot experience. One for the combined MND/LC group (Table 6) and one for the professional carer group (Table 7). Although these were slightly different, three principles remained consistent: prior information about the study was given to participants before meeting with the researcher, two visits were made to conduct the guided conversations and thirdly, all participants received a full transcription of the first conversation to validate their accuracy.

Table 6. **Protocol for collection of evidence - MND/LC**

Visit	Activity	Time frame
Visit 1	First meeting to potential participant (s) as identified by voluntary visitor and accompanied by MNDA voluntary visitor. Explanation of aims of the project, their involvement and ethical principles. Guided conversation schedules discussed and left for them to examine at their leisure. Provisional date arranged for second visit with researcher. Contact number left for cancellation or rearrangement	Day 1
Visit 2	Conduct guided conversation with MND alone	Day 12
Visit 3	Conduct guided conversation with LC alone	Day 12
	(Transcribe conversations and send to participants)	Day 38
Visit 4	Conduct interpretive conversation with MND	Day 60
Visit 5	Conduct interpretive conversation with LC	Day 60

In practice this protocol was adapted to suit the participants. For the MND and lay carers this often resulted in three visits. I was invited to talk first with one partner alone and then the other on the same visit. Such visits were exhausting and demanding but suited the needs of the participants. It was judged important to meet with them as individuals to offer them the freedom to tell their stories as independent persons despite their interdependence. In the case of couples 5 and 6, their partner entered the room as the second conversation was concluding and they joined in for the last 15 minutes. This did not have any obvious adverse effects.

The MND sufferers were able to offer written evidence in addition to oral as they responded to the conversation prompt sheets. This process allowed MND participants to construct their responses in advance of the meeting. They were doubly useful as they supported the researcher's attempts to interpret the dialogue. The protocol was different with professional carers. Two visits were required as the introduction was via telephone calls, as indicated in table 7.

Table 7. **Protocol for collection of evidence - Professional Carers**

Approach	Activity	Time Frame
Telephone call	Initial telephone call by the researcher to establish their willingness to participate in the project and to reassure them that MND/LC3 had given permission. Overview of project given with assurance of ethical approval and their time involvement. Negotiation of convenient time for first guided conversation	Day 1
Visit 1	First meeting clarified aims of the project, their involvement and ethical principles Guided conversation completed without PC's previously seeing the conversation prompt (Full transcription sent to PC prior to second meeting)	Day 5 to Day 100
Visit 2	Interpretive conversation	Day 49 to Day 130

4.7. THE GUIDED CONVERSATIONS

These conversations were designed to encourage participants to offer their experiences of every day worlds. Exemplars were encouraged through story telling to illustrate their experiences. Cue questions were established to maintain the focus on care but were only used as necessary and in the manner of prompting clarification rather than direct questioning. This approach differs from an interview approach which involves question and answer tactics.

MND participants and their lay carers were given copies of the guided conversation schedules. This action was to offer them the opportunity to make an informed choice about their involvement in the study which was recognised as potentially stressful. The professional carers did not see the conversation guide prior to the first meeting. On reflection, this same opportunity would have been appropriate as it could have assisted in clarifying the nature of conversation in more detail.

4.7.1. Tape recording the conversations

Each guided conversation required concentration on behalf of the researcher. There was the need and desire to develop a relaxed environment, concentrating on the participant but offering comments of encouragement and seeking clarification where necessary. In addition, the stories being told could be quite distressing. Throughout the conversation the researcher needed to remember that collection of evidence was a major consideration and that how initial interpretations were being understood was focused in the researcher's own experiences.

Conversation requires a mixture of genuine attention, eye contact, trust, listening skills and verbal exchange to encourage people to tell their stories. As they were audio recorded, these events and episodes could be transcribed as text. It is recognised that no research conversation can be considered 'normal' but the aim of the guided conversation was to make it as non-threatening, genuine and as 'normal' as possible.

The 21 guided conversations were tape recorded to allow an accurate record to be kept. The tapes were able to record an hour each side. This reduced the need for their further attention once activated.

In hermeneutic research, the text is the unit of analysis to 'bring to light an underlying coherence or sense' (Taylor 1985:33). This process can be more complex than first impression allows. A conversation may elucidate stories but can mean the information is less organised than interviews. Guiding the conversation however, is the attempt to keep the focus for both the researcher and participant. On occasions the focus of the conversations became random due to the excitement of the story teller but the researcher did not wish to restrict the participants although attempts were made in guiding them. This made the transcripts more challenging to analyse. The speech difficulties of the MND participants meant that the researcher often had to re-iterate sentences to capture the participants 'words' on tape.

4.7.2. Guided Conversations with Cared For

Two questions guided the first conversation. They were designed to enable the participant to talk freely and tell their stories about their experiences of being cared for (see appendix 3).

Cue questions had been prepared to be available as necessary to keep the conversation focused. However, in practice, the conversations with the cared for group flowed freely. They welcomed the opportunity to discuss their experiences and thoughts.

The longest interviews occurred with this group of participants (90 minutes) because they became emotional and tired. Whenever I offered closure they refused.

The conversations were spontaneous and free which was positive in that the participants chose the direction but this resulted in challenging analysis of the transcriptions. There was some repetition throughout. However, it can be argued that this reflects a typical conversation in relating one's story to another whilst emphasising certain points. Attempts to alter their flow were gently rebuffed and they returned to their own agenda. The conversations often appeared therapeutic for the participants. They appeared to value the opportunity to give voice and for that voice to be attended to by another.

After the first interview, they were formally thanked for their participation and sent a copy of the transcription to read for accuracy. Thereafter I made contact by telephone to arrange the second meeting.

Invariably the second visit was emotional with shared sadness. All clearly had physically deteriorated and we both realised the significance of the passage of time. Essentially we knew that the farewells were goodbyes. I found this parting personally very stressful on two counts, one for their sake as they must be saying many goodbyes and I was adding a burden to that list. Second, as I had engaged with them and shared part of their dying moments in a close encounter I could feel myself mourning for them as I left. These emotions meant that the visits were very demanding as well as a privilege.

All the interviews with the cared for were emotional experiences for me in the role of researcher. I was able to readily connect with them, to find and meet them where they were emotionally. However, there were many difficult moments when my silence and attentive listening was all I could offer to the experiences recounted. I became very focused and immersed with them, leaning forward, sometimes touching a hand or offering a hug but always maintaining attentive, non-threatening eye contact. I used my eyes to offer expressions and emotions of compassion and understanding.

Many of the MND participants had speech difficulties which extended as they became tired. I learnt to "tune in" to their context and after a few minutes to lip read. When I was with them I seemed able to engage and hear them. Being with them and hearing their stories and emotions was rather like talking to someone in a foreign language, the sense of the meaning being absolute even if the tongue was imprecise. Field notes were a great help and highlighted the desirability of the transcription to be verified by the participant and modified as necessary in the second conversation.

4.7.3. Guided Conversations with Lay Carers

The guided conversations followed a similar pattern to the cared for with a modified focus (see appendix 4). The lay carers were keen to record their views. Similarities with the MND group became evident in that their stories were emotional and needed no active response from the researcher to reinforce their trauma. Personal relationships were quickly formed, due to the intimacy of the situation, this led to sadness on completion of the second meeting. Many lay carers experienced particular difficulty with their future plans as they had concentrated exclusively on their current role as carer.

4.7.4. Guided Conversations with professional carers

Re-entering the world of professional carers was a strange personal transition. It was familiar but alien. I had learnt so much from the other two groups that I could not help but consider the professional evidence from their perspectives. It made me realise how my own prejudices had been altered through collecting evidence in this order. I now had to consider these new prejudices as influencing my interpretations of the professional evidence and be reflexive in this process.

These carers presented themselves as busy professionals with little time to offer. This was particularly marked for the first conversation when they appeared to 'fit me in' rather than welcome our interaction. Indeed, apart from PC7 who invited me to her home outside her working day, I was scheduled into their busy diary of out-patient appointments or meetings.

This process of forced accommodation resonated with evidence recounted by the lay participants.

The importance attached to our meetings varied with the majority arranging un-interrupted meetings while a significant proportion appeared to attach greater significant to their casual interruptions. This latter approach contrasted strongly with the exclusivity offered by the MND lay carer participants. This contrasting culture highlighted the significance of those seeking a service to those offering one. I can only speculate that how I was received could mirror how the patients were received.

The conversation guide consisted of two main questions in the first visit and three in the second, with cues as appropriate (see appendix 5). The professional carers had not seen the conversation guide prior to their first meeting with me. In four instances it may have been preferable for them to have seen the guide as they stated they found the emotional/personal areas challenging and may have benefited from some reflection to think about them. However, I attempted to minimalise this problem by revisiting these areas during the second visit.

Throughout the first conversation, I attempted to gain the confidence of the participant through being non-judgemental, supportive and practising genuine attentive listening. They had difficulties linking their care experiences of a personal nature into their practical, professional activity. For example, there was much discussion concerning professional assessment but when the conversation moved to how a professional copes with a person who has a terminal illness and what guides such coping, this was often discounted as just part of the job. It took persistence to break through to the person behind the professional. When this was successful their persona became more evident and at the second conversation I was greeted with a more relaxed demeanour. I realised how professionals are not readily listened to in terms of their own needs and how this was a problem for them. Once confidence was secured, they were much more forthcoming and open with me and interested in the study.

4.7. SUMMARY

This chapter has presented the trail involved in organising the main study. Ethical considerations were addressed affecting the whole study. The conduct of the pilot investigation served to influence the main study design through the learning gained by the researcher. The main study is explained in terms of sample access with introductions to establish their credibility. The guided conversation protocols and conduct are clarified with evidence of the researcher's journey adding to context and situatedness of the researcher.

The next decisions involved phenomenological reflection and interpretation of the textual conversations, 'to try to grasp the essential meaning of something' [caring] (Van Manen 1909:99). The following three chapters offer insight into the interpretative analysis trail.

CHAPTER 5: ANALYSIS TRAIL

5.1. INTRODUCTION

This chapter presents the interpretive analysis trail of the texts originating from the guided conversations. Three trails are constructed which reflect each group of participants. Each group is addressed separately to illustrate the process. As the evidence is copious, only the cared for trail is presented fully in the chapter with the lay and professional group evidence located in appendices 6 and 7.

The findings have been influenced by the prejudices of the researcher, her interactions with the participants, research supervisors and the research context. It is expected that the reader may construct and reconstruct their own interpretations based on their prejudices, histories and experiences. This process of understanding and interpretation is a never ending journey as Weinsheimer (1985:177) reminds us, as 'our own understandings, like those of our predecessors, however apparently definitive, never seem to be the last word'. The important dimension is that the interpretative trail should be clear, allowing the reader to follow it and begin their own conversation and interpretation with the text.

The first four stages of the analysis process are presented. The next three chapters address the final stage from each participant group. Chapter nine presents a comparison of similarities and differences between the three groups, culminating with the construction of professional learning recommendations and the lay and professional model of caring.

5.2. FIVE STAGES OF THE ANALYSIS PROCESS

The development and justification for the analysis process is explicated in chapter three (section 3.5.2.). These stages are summarised in table 8 and Figure 5.

Table 8. The Analysis Process

A: Hearing and Writing the Story

A1. Read transcription from guided conversation to engage with the story as told, the text.

A2. Write out the story as understood to gain a sense of the whole before entering into detailed analysis

B: Hermeneutic Interpretation: revealing meaning

B1. Question what is being meant in the stories. Use one's prejudices to raise these questions from each individual text which offer some insight into questions of what is being meant?, what matters? what is it like? what is being learnt about care/caring?

B2. Extract significant statements from each individual text which offer some insight into questions of What is being meant?, What matters? What is it like? What is being learnt about care/caring?

B3. Cluster these significant statements from each individual text to formulate interpreted meaning themes (first level themes) as interpreted by the researcher (link meanings of experiences with the statements)

C: Learning through dialogue

C1. Return to each participant to present the interpreted first level themes for further dialogue (Dialogue for fusion of meaning, being aware of one's prejudices which have influenced interpretations). Second guided conversation for asking: Is this what the experience is really like?, This is what I understand you were meaning, This is what I learnt, do you agree? With evidence from significant statements (Validating stories and opening fusion possibilities but allowing to move on to the interpretation).

D: Fused Thematic construction

D1. Establish the second level themes through constructing a fusion of the first level themes (B3) through the dialogue (C1). Establish the second level themes from each transcript by weaving in the original themes from conversation 1 with those that emerged from conversation 2 (the fused horizons).

D2. Cluster similar themes from each individual to form individual categories. These represent commonalties of values expressed from their stories. Identify themes which represent difference.

D3. Construct categories for each group, from the themes and categories of the individuals. Select statement exemplars from original transcripts to illustrate the categories.

E: Conceptual model of phenomenon(a)

E1. Compare categories across the three groups for similarities and differences
E2. Formulate conceptual framework for lay and professional values of care

The analysis process is presented through illustrations for each of the three groups. The cared for group trail is supplemented by a supportive commentary and includes participant stories and the researcher's reflective insights. Once the analysis trail process is established the illustrations from the remaining two groups are more focused, there is no supportive commentary and the main stories are found in the appendices 6/6a and 7/7a. This approach has no intention of detracting from the lay carer or professional carer accounts but has been formulated for expediency.

Figure 5. Diagrammatic Representation Of Analysis Process

Action	Stages
Story presentation	A. Hearing and Writing the Story
Identify significant statements	B. Hermeneutic interpretation
First level themes	C. Learning through dialogue
Second level themes	D. Construction
Individual categories	
Major group categories	
Group conceptual model	E. Conceptual model of phenomenon

Conceptual framework for lay and professional values of care

5.3. THE ANALYSIS PROCESS FOR THE CARED FOR - PATIENTS WITH MND

The six participant guided conversations resulted in 10 transcriptions (texts) from their two guided conversations. It is not possible to offer the trail for all six participants so one person with MND, Mrs Pam Six, is presented to allow the reader to appreciate the style and approach taken. It was not a straightforward decision selecting one person for this purpose as all had significant individual stories to offer. The criteria I employed were as follows: she was in the median age range of all the participants (54 years), was female and therefore the dominant gender of the participants (four women and two men); had gross dysphasia and dysarthria. This presented its own problems but this illustration demonstrates the success of the solutions.

The analysis was an iterative process and although every attempt is made to explicate the decision trail, it is challenging to report in a linear approach. Each identified stage is considered in sequence.

5.3.1. A: Hearing And Writing The Story - Entering The Hermeneutic Circle

Each audio recorded conversation was transcribed to gain a text and then repeatedly read to gain a sense of each participant's story. This action aids the researcher to enter 'into the hermeneutic circle properly' (Bleischer 1980:103). Writing out the story in one's own words encourages close engagement with the story and the context as it deepens familiarity and understanding of the text. The written story need not be long but includes personal aspects of the researcher's engagement taken from the field notes and reflective journal. This allows the researcher to re-enter the experience and re-capture the conversation. The importance of drawing on the text and reflective diary field notes culminates in capturing the context, environment, actions, prejudices and feelings during the conversation.

In writing, the aim is to outline each story in relation to content, meaning and mode of telling (sad, hopeful, angry, critical, engaged, detached etc). The image of the self as presented by the narrator (participant) in the text can be captured through this process (Mischler 1986). The personal identity to which the narrator is laying claim through his or her account can be appreciated which is supportive to value exposure, their personal framework of meanings. In addition, the image of self as presented by the researcher can also be captured. This writing process offers an act of projection; the gaining of a sense of the whole before the detailed analysis. This involves further reflection, assimilation and questioning which is the aim of the interpretation. As Gadamer suggests, 'The hermeneutic task becomes of itself a questioning of things' (cited in Weinsheimer 1985:167) where we integrate the meaning of the text with our previous perceptions, 'by making them conscious, bringing them into view, and assimilating them to what the text reveals'.

Through using prejudices to make projections, they cannot be eliminated but one can learn to know them as one's prejudices from one's social and personal histories. As Weinsheimer (1985:175) suggests, this is a

> 'method that makes use of our prejudices and sorts them out...in the process of interpretation itself. This is the whole-part method of exegesis, the circular method most often associated with hermeneutics itself'.

Anticipation of the whole may well occur before it is reached but the parts demand rigorous analysis to check the prejudice of the whole. The following example offers an illustration of this process from MND Six.

Example of a written story from a transcribed text - MND Six (Pam)

Reflections prior to engaging with Mrs Six

Before meeting with MND Six, I was beginning to feel exhausted and emotionally stretched. I had already met five other people with MND, and their five lay carers and one MND participant had already died. The emotional effort of making a relationship with a person over a short time period was beginning to tell. Hearing and seeing the terrible effects of MND on their bodies and personal resources and being instrumental in them spending precious moments of their remaining time with me was creating an enormous sense of responsibility, privilege and distress. The prospect of meeting another person who would deteriorate over the course of two meetings was an emotional challenge I did not relish. Linked with this was the knowledge that if I was feeling these thoughts and emotions I must be gaining some insight into the experiences of the lay carers, professional carers and perhaps the cared for.

Introduction to MND Six

MND Six was a lady in her 50's from a professional health care background. She had raised a family of two boys almost single-handed as their father had been in the Services and often absent from home. Her sons were now both in their 20's and she was very devoted to them. She was self-reliant, independent and competent at managing her professional role, the household and caring for an elderly mother before she was struck with MND. She presented as having a very warm nature, a great deal of enthusiasm for life through her communication with people. She had a spiritual commitment, took obvious pride in her personal appearance, had a strong sense of protocol in social interactions and clearly identified that her family was her priority in life. She told her story with emotion and passion with an absence of bitterness or hatred.

The introductory meeting

I recognised that the MNDA Voluntary Visitor and Mrs MND Pam Six had a very strong relationship of mutual respect, kindness and friendship. Into this atmosphere I was warmly welcomed. It immediately released some of my 'field fatigue'. I was instantly moved by Pam's enthusiasm to talk with me about MND. This was not unusual as all the previous MND participant's has been keen to explain their situation and offer their stories.

We shared a pot of tea which Pam made with her friend's help. We had a joke about a new freezer that had been delivered for the third time and was still not working properly. On this warm sunny day we sat in her beautiful lounge with the sun pouring through. My concerns were building however in terms of how I would cope with talking with Pam on her own. Although she was fully mobile her speech was very dysarthric and I really had to concentrate to understand her. It was like hearing a foreign language of which I had a limited understanding. The visit lasted about an hour, during which I gained confidence in her language through her gestures and distorted speech. My contextual concentration and anticipation grew sharp which was coupled with her patient attempts at clarity and precision.

I began to 'tune in' and made progress so I explained the research project, the sorts of areas I was interested in learning about from her and her time and role commitment to the study if she was willing to participate. She agreed immediately and wanted to start telling me about her journey to a diagnosis. I listened attentively but reminded her I needed to return so I gently asked her to think about her participation and offered her the sheet of paper with the possible areas for discussion next time. This she took and arranged a date for a future meeting. I felt as if she really wished to begin there and then, that she knew her time was limited to tell her story. Reluctantly I knew I had to offer her space to consider her involvement.

The first guided conversation

My first visit alone to Pam was a success in many ways. Pam was able to offer her story, I was able to appreciate it. Although there were challenges with the communications I ensured a text was being captured on the audio tape. We soon created a warm environment of mutual respect and trust between us. She was eager to start, so after a hot drink was made, we again sat in her lounge and we began. She started to communicate with me immediately and talked quickly which made her even harder to understand. In her enthusiasm, I could feel her frustration at not being able to tell me about her experiences quickly enough which I felt were brimming over the top. She switched on her light writer and we began to settle into a form of communication beyond my experience. I had to learn fast and it required an incredible effort of concentration and attention on my part, as well as hers. Through her mouthing words with some audible and some non-understandable sounds I tried to lip read. Combined with the light writer, hands signs, body language and my anticipatory or retrospective interjections of words for her to accept or reject, we progressed. She also produced written notes in response to the tentative questions I had left for her from my last visit. These helped me to 'tune-in' quicker.

When she was using her light writer, she indicated that if I understood her sentence before she had finished it that I was welcome to interrupt her to finish the sentence. I was surprised by this request as I had previously been told by a nurse involved with caring for people with MND that they did not like being interrupted in this way. I quickly adapted my stance to accommodate her request. It was a little like verbal charades.

Pam's MND story

She told her story with laughter, tears, distress, determination, patience, frustration, suffering and humour. It was an open account from the heart, which was something I recognised as common amongst the MND participants.

She had been diagnosed for a year when we met. She was fully aware of the 3 months to 3 years prognosis. Speech difficulties had been her first presentation when people had thought she was drunk because her speech was so rolling. She was disciplined at work because her manager thought she was drinking on duty. Even her family expressed their concerns about a possible drinking addiction. Her husband would telephone her in the evenings from his office and think she had been at the sherry.

Being a health care professional herself, and having cared for people with MND, she knew her diagnosis early on although she initially denied it. It was too horrible to face and she convinced herself her symptoms were from being over tired. She did not share her concerns with her husband as she wanted to protect him. He worked away from home a great deal and was on the verge of an important career move and she knew how it would affect him. She also did not want to admit the possibility to herself. She explained that when she did go to the doctor and received the diagnosis it was a terrible blow for her to hear the reality.

She described herself as being a spider in a web; she was at the heart of her family and kept everybody together. She was still trying to continue this role even though she knew her web was breaking down due to her increasing physical deterioration. She had always been the coper and was concerned at becoming a burden to her family and the family's financial resources. This prompted her to having a feeding line inserted early on (PEG) so she could maintain some physical strength even when she could no longer eat and drink normally due to the increasing bulbar palsy. In terms of financial resources, she was rather reluctant to buy things for herself but agreed to home extensions (conservatory, downstairs bathroom) as this would be a sound investment as well supportive to her.

In knowing that she was going to die soon but not knowing when, she set her herself goals to reach before her death. One was to stay alive long enough to see her eldest son graduate. She recognised that her long term life plans were broken, that of seeing her sons marry and have children of their own, and being a grandmother. This loss of her future was very distressing for her.

The increasing erosion of her former normality urged her to attempt to recreate a new normality. She had left work but turned her attentions to the decorating and extension plans of the house as her new work. She could no longer look after her mother but kept in touch by telephone.

She could no longer care for the home but had employed a housekeeper whom she instructed. She could no longer bake cakes and make marmalade but employed a social carer who could help her with these endeavours. She was very much a homemaker and wanted to keep this role in whatever form for as long as possible. Despite all her strategies for recreating a normality she felt desperate that she could not *'do'* for her family. In terms of outside help, she was strongly opinionated that a patient needs to get to know their carers and that different individuals should not be sent. This relationship through 'knowing' applied both ways and applied to professional and social carers who supported her.

She knew her speech would deteriorate further so she was prepared with communication technology; a fax machine, and a ansaphone with buttons for her to chose a pre-recorded message. Her main problem at this stage was the deteriorating speech and the resultant inability to be understood. This created her greatest frustration, loneliness and pain.

She explained how she was clearing out the attic giving her things to her family. I enquired whether this action was her caring for her family by trying to tidy up lose ends that might otherwise trouble them later. She had subconsciously been doing this but only realised that explicitly, or admitted it to herself, through our conversation.

Her reaction to MND was that it was terrible and she felt cheated out of life. She stated it is 'the pits', a terrible way to die, 'a bit like a crushing ivy killing off a healthy tree'. She had learned very quickly to live for each day and not to plan too far ahead only to see her plans dashed. She experienced frustration that she could not do all the things she used to but the worst was the speech. She told me only her youngest son and best friend can really understand her now. She refers to her best friend as 'MAOE', my angel on earth, who is her greatest carer as she can 'sense' what Pam is thinking, needs and wants.

As her physical mobility and independence deteriorates her greatest fear is requiring more help with hygiene matters, in particular going to the toilet. In addition, she is embarrassed how her bulbar palsy is making her make noises when trying to swallow and cough which she describes as 'being like a pig'. To this precise lady, such behaviours are anathema and distress her greatly.

5.3.2. B: Hermeneutic Interpretation - Developing The Meaning

During conversations there are spontaneously perceived discriminations (Giorgio 1985) arising from prejudices of the researcher. Therefore it is necessary to harness the hermeneutic consciousness in 'our ability to see what is questionable'. (Gadamer 1976:13). This is the quest to discover what is being meant, learnt or is not understood, which can then be checked out with the participant. This necessitates the researcher engaging with the text in more detail to avoid de-contextualisation and to consider the questions the text is answering and posing; what is left unsaid, what is the implicit nature of the phenomenon under examination, how does it show up, how does it happens, what is its temporal nature and how do particular situations link up with each other?

The hermeneutic interpretation stage is to ascertain what has been understood and learnt through writing the story (interpretation) and to try to present the whole story through its parts. This involves identifying clusters of significant statements in relation to caring and the experience of living with MND which can then be confirmed with the participant. A questioning process is paramount; before and during the guided conversation, whilst reading the text and through the writing of Pam's story. Questions included; What am I learning from her? What does she mean, what is she trying to say? How can I understand? What are my prejudices in my learning/interpretation? How does she care for others? How has she experienced caring from others? What are the values determining caring and being cared for? How does her story help me to understand caring better? Do the first themes I have developed reflect care? What is still puzzling me?

As these questions were considered, certain phrases became obvious as offering answers. On first realising something was wrong she described how she initially 'pulled down the shutters', a deliberate act of blinding herself to the awful shock of the reality. She suspected MND but could not bring herself to go to the doctors or talk to her husband about it as she knew it was 'too horrible, too horrific to open the door and look in'. She accepted disciplinary action at work with the accusation of being drunk when her speech deteriorated to a level of slurring beyond an explanation of tiredness. She also absorbed similar accusations from her family who thought 'she had been on the sherry'.

These actions of 'purposeful blinding' and 'shutting out' she also enforced on her husband. She did not inform him of her illness, leaving him to think she had been drinking. When she finally received a medical diagnosis the reality was a shock but almost a relief as 'the door was open and it was real. There is was and now you knew you had to deal with it'.

These significant statements answer questions of how she dreaded the confirmation but also needed the official label, how she couldn't be the one to tell herself or others, how she was trying to protect herself through initial personal denial and protect others from the horror of the diagnosis and what would follow it. Her metaphors of the closed shutters and doors assisted my understanding of her personal pain, her initial lonely struggle and her fear through this time. Her story suggested to me that Pam was trying to protect herself and her family from a possible 'horrific' reality. These statements in her story lead to two first level themes; 'Protection' and 'Initial denial'. The choice of significant statements demanded the researcher made judgements about what she thought was significant in relation to the phenomenon in focus. Once these significant statements were identified they were clustered into tentative themes.

Although I labelled a theme of 'Protection', Pam's actions would be contrary to my own behaviour or prejudices. Her story therefore broadened my experience and understanding of a person's response to a distressing diagnosis. Although I can appreciate her behaviour and protective values, if I was worried about a serious personal illness I would react differently. I would worry myself and then everybody else about my suspicions before going to a doctor. I would want everyone else to try and 'pull down shutters and shut doors' for me, to reassure and possibly protect me rather than me being able to do this for others. This dissonance challenged me to 'find a common sense between the strange and the familiar' (Weinsheimer 1985:184).

If I encountered meanings outside my known prejudice, I needed to question these meanings and my prejudices to deepen my understanding. I should not dismiss the other horizon but consider it, to widen 'one's own horizon so that it can integrate the other' (Bleicher 1980:112-113). I needed to discuss this first level theme with Pam during the second conversation to confirm the interpretation through my expanded horizon.

5.3.3. C: Learning through dialogue

Returning to the participant for the second conversation enabled further dialogue for the researcher to question the first level themes and to construct the second level themes. At this stage, all themes were still individual to each participant and had not yet been aggregated or clustered with other individuals. This dialogical process in hermeneutic research would usually be between interpreter and text, but the theoretical justification for returning to the participant is offered by Bleischer (1980:144)

'the concepts used by the Other, be it a text or a thou, are regained by being contained within the interpreter's comprehension. In understanding the question posed by the text we have already posed questions ourselves and, therefore, opened up possibilities of meaning'.

The first level themes can be viewed as questions which the researcher believes help to understand the phenomenon of caring. Checking these themes with the participant allows for confirmation of meaning or repudiation with the possibility of meaning to be constructed together. The aim of the second conversation was to explore the first level themes in the context of the following questions; this is what I am understanding (my horizon), can I check this out with you? This is what I have learnt about caring from you, can I question whether this is what you meant? What do you mean by x? Can you identify the meaning behind this theme as explaining care/caring? (there may be multiple realities from the language of the participants). Is care and caring the key process in this theme? Does something else arise? What did you learn about care/caring from our first conversation? Did the first conversation affect you in any way, if so can you explain?

Summary of second conversation with Pam

The second conversation took place four months later. I was greeted at the door by her husband who led me into the lounge where she was waiting. On seeing her I realised she had deteriorated both in terms of her speech and her general mobility. At one point I had to help her get up from her chair which she could manage on her own before. She did not have a cup of tea with me as she could no longer swallow it very well and did not wish to do this in 'public'.

She had read the first transcription of our conversation and agreed with its accuracy which was an important point due to the challenges in the transcribing. I presented a synopsis of the first level themes I had developed for our discussion. She had her light writer to help her communicate but we reverted to our previous communication experience using sign language, mutual anticipation and facial expressions. I had to verbalise what I thought she said for her confirmation or refutation and to make an audio recording.

I asked her whether she had been 'protecting others' and had experienced 'initial denial' both to herself and her family from the diagnosis in the first instance. I drew her attention to her metaphors of 'shutters' and 'doors' which she reinforced by her gestures and body language. She indicated that she was protecting others and trying to deny to herself the possibility of MND. She elaborated that it was such a terrible thought, that of having MND, that she did not want to face it. If she told others her thoughts then that would have meant her having to face it, as well as others. In suggesting that she was trying to be caring of herself and caring of her family through protecting them from any unnecessary harm until it was confirmed, we both were able to fuse our horizons of understanding. There was a broadening of my horizon and with her a heightened awareness that she was actualising her caring value of protection through her behaviour. This led to a merger of the two first level themes into one second level theme; 'protection from shocking reality'.

We discussed the other first level themes which arose from her text and we met similar situations where she could appreciate how the interpreted themes had been arrived at. Her horizon of understanding was heightened through my interpretation of her actions in clearing out the attic for the children. My tentative theme was labelled 'Clearing her path'. She had stated that 'I am in the process of listing treasures and giving them away, giving history'. She did not want the family 'to have muddles' as she believed her husband would not be able to 'deal with it' on her death. As a result she had 'everything boxed now with names on it' and had 'given them instructions as to where everything should go'.

When questioning these actions I concluded that if I was in a situation of leaving somewhere, in my realm of experience such as work or an office, I would clear my desk so it would not trouble anyone else and it would also close a chapter for me. Her action of clearing out the attic suggested to me that she was clearing up her path and in the process make her family's life easier in terms of disposal of items on her death. She realised that tidying out the attic would allow her to have some control in the disposal of items, which was particularly important to her as she was struggling for control over her future. However, she had not viewed this action as holding a caring value. That caring value was reducing their trouble on the event of her death, preparing for her absence, through these forced life changes. It was also the beginning of a closure for her to her life but was also a measure of her taking some control over her future death.

I knew after the second conversation that I would not see her again and indeed I did not. It was a difficult parting for me as I had been privileged to be taken into her home, hear her story and inner most fears and frustrations, meet her family and share some of her precious time. She had re-energised me through her courage and for her she stated the effects of our conversations had been to 'put things in perspective, put some thoughts into [my] head, put some thoughts into boxes. [I] hadn't thought that that's what [I was] doing before so it raised [my] awareness'.

Hearing personal histories and offering back abstract themes presents experiences in differing ways as both are interpretations. Through dialogue, if consensus is sought and reached, the meanings behind personal histories can be crystallised. Long stories are time consuming to tell but abstract themes can be equally telling when grounded in personal histories and with agreed interpretation between the teller and the interpreter.

5.3.4. D: Construction

Once individual second level themes are established, these are clustered into individual categories. The interpretation process at this stage can continue to draw upon other explicit sources as the 'interpretation becomes a merger of data sources, or a construction' (Koch 1995:176) which can include literature, the text and the entries from the reflective diary of the researcher. In the search for categories however, Frank (1997:85) suggests that 'categories are not an end in themselves' but the willingness of the researcher to 'stay tuned' to the participants and aid the researcher to 'observe how they adapt and transform new situations, reinventing the meaning of their activities and lives'.

The second conversation served to assist in this process. Table 9 illustrates the clustering of Pam's identified second level themes into two individual categories.

Table 9. Pam's themes to categories

First level themes	*Second level themes*	*Individual Category*
Protection Initial denial	Protection from shocking reality	The shock of MND
Clearing up her path Giving body to science Making Will Giving away history	Preparation for absence	Loss and struggle for some control

When individual categories were completed for all six MND participants they were examined collectively and major group categories were constructed. Nine major categories were constructed (see appendix 8). The two individual categories from MND 6 were incorporated into the major categories 'Existential Shock' and 'Struggle with increasing loss of control' as illustrated in **bold** in table 10.

Table 10. Development of MND major group categories

INDIVIDUAL CATEGORY	MAJOR CATEGORY
MND1The shock of MND MND2 Horrors and uncertainty of MND MND3Destroyer of life MND4 Journey through the diagnosis MND5 Journey to the diagnosis **MND6 The shock of MND**	**Existential Shock**
MND1Forced life changes MND2 Knowing deterioration MND3 Need for a sense of control MND4 Constraints on life MND5 Struggle for personal control **MND6 Loss and struggle for some control**	**Struggle with increasing loss of control**

5.3.5. Summary of MND analysis

This journey has offered evidence of the MND participant analysis decision trail using extracts from the text. It began with the story of MND6 and demonstrated the construction of first and second level themes leading to individual categories.

It concluded with an example of individual categories merging with individual categories from other MND participants into major group categories. The next two sections offer a more direct illustration of the same process for the lay carer and professional participants.

5.4. THE ANALYSIS PROCESS FOR THE LAY CARERS

Six lay carers completed two guided conversations each which led to twelve transcripts. The evidence from one participant in this group is presented as an illustration. LC Three was chosen to illuminate this process as she was one half of the partnership who identified the 'good team' of professional carers.

5.4.1. A: Hearing And Writing The Story - Entering The Hermeneutic Circle

My reflections prior to engaging with LC Three are presented below (turn to appendix 6 to read her first guided conversation story).

Reflections prior to engaging with LC Three (Jenny).

As the number indicates, LC Three was the third lay carer I met in the main study. I was well into the field work but still with a long way to go. I had already met two lay carers, a lady in her mid- 60's and a gentleman in his early seventies. Although their stories were unique, I considered I was gaining a sense of the lay carer's experience; how hard and demanding it was but also how they felt they had no option to refuse their role. They loved their partners and therefore decided caring and coping was right and expected, although challenging. I was now feeling more confident in the role of researcher and comfortable with the format of the guided conversations. The two main questions were being well received and the cues had been useful on occasions. However, I went with a special anxiety to this meeting as there was potential for personal identification. Jenny was of a similar age. To date, MND and its effects has been a senior citizen disease to me, I was about to enter a world nearer to my own.

5.4.2. B: Hermeneutic Interpretation

Jenny's story, (see appendix 6) spoke at length about trying to create new routines under difficult circumstances. She was being forced to recreate herself by adapting to new responsibilities and how caring for Henry was influencing her world. Using exemplars from her story and identifying their significant statements, I was able to construct two interpretative first level themes; 'Being different but the same' and 'Shifting roles'

Significant Statements supporting LC First level theme: 'Being different but the same'

'my life revolves around Henry's life now' (LC3)

'we do all try and sit down together' (LC3) for meal's although her husband was being partially tube fed.

The importance of this was 'for everyone really. It's for the children and us and also a kind of feeling that we're not going to let it spoil everything' (LC3).

Significant Statements supporting First level theme: 'Shifting roles'

'Just before all this happened I was looking for a full time job and now I feel this is it' (LC3).

'It's a kind of sadness. I remember saying you've got this picture of yourself walking off hand in hand into the sunset and that's just kind of gone' (LC3).

'suppressing unhappiness, the sadness of the situation [and if] you've got to get on with it and live your life anyway so it's kind of kept down as it were' (LC3).

'but when I feel about achieving things like driving the car I feel I've more confidence in myself and sometimes proving to myself that I can cope with the situation I'm becoming more confident and assertive' (LC3). This change for her was seen almost as a sliver lining to a really most impossible situation.

5.4.3. C: Learning Through Dialogue

My return to Jenny for the second conversation (see appendix 6a) to confirm these and additional first level themes was an interesting interview. She agreed with all the first level themes I suggested and we did not have to discuss any variations in interpretation. It seemed as if my horizons and prejudices were tuned into her reality and situation, permitting development of congruent meanings from her evidence.

She did share new insights into adapting to coping more with her situation. This highlighted how time can influence situations, values and behaviours whereas others remain constant. This new information led to the further development of themes which I confirmed with her during the second meeting.

5.4.4. D: Construction

With agreement on the first level themes, second level themes were not necessary as our fusion of horizons was achieved. This meant that the first level themes were used to construct the individual categories. A collection of parallel first level themes were therefore merged to construct the individual categories as illustrated in table 11.

Table 11. Jenny's themes to individual categories

First level themes	Individual categories
Being different but the same Striving and working for normality Importance of normality for the children	Re-creating normality
Shifting roles Full-time job MND taking over and changing my whole life	Life changes

Once Jenny's individual categories were established, the six individual participant categories were examined together and this allowed construction of ten major categories for the lay carer participants. An example from Jenny's individual categories is offered in table 12. The full analysis is presented in appendix 9.

Table 12. Development of lay carer major group categories

INDIVIDUAL CATEGORIES	MAJOR CATEGORY
LC1 Response to forced changes to lifestyle LC2 Loss of own life **LC3 Life changes** LC4 Forced restrictions LC5 Forced personal losses LC6 Forced changes on carer	**Forced life changes in caring for another**
LC2 Normality before reality **LC3 Re-creating normality** LC4 Striving to maintain a normality LC6 Denial of reality	**The False Normality**

5.5. THE ANALYSIS PROCESS FOR THE PROFESSIONAL CARERS

There were nine participants in this group which led to seventeen transcripts. The evidence from one participant from this group is presented to illustrate the analysis process. As the professional carers came from differing disciplinary backgrounds a decision to select one participant was taken based on which professional carer's individual categories contributed most evenly across all the major categories. This was identified as PC7, the physiotherapist.

5.5.1.A: Hearing And Writing The Story - Entering The Hermeneutic Circle

The PC stories were markedly different from the other groups and presented their own challenges. The PC stories were not about personal loss and distress, shifting roles and preparations for death but were about strengths, ideals, awareness of role limitations, and inter-professional co-operation. There were some parallels to the MND/LC groups in areas such as learning to care and the awareness of the critical nature of time.

As identified in chapter 4, four of the PC's had never cared for a person with MND before, four had only met 5-10 cases before and only the neurological consultant had experienced over 100 cases. The physiotherapist (PC7) acknowledged she had cared for one person with MND in a hospital setting and in the community had come into contact with at least 10 cases. The story from PC seven can be found in appendix 7. Reflections prior to the first meeting are offered as follows:

Reflections prior to first conversation with PC Seven (Ann)

I had met with PC Seven on one occasion before our first guided conversation. I had been with a person with MND and her husband when Ann made an official visit. After introductions she appeared interested in the research project. When she was identified by MND/LC 3 as their physiotherapist, I realised that the professional caring world for people with MND must be quite limited. She worked part time so I had to leave several messages and locate her working pattern before I talked to her personally. The telephone conversation was very positive as she agreed to talk with me and invited me to her home rather than work to ensure privacy. She appeared a lively individual who was confident in her own skills and profession and willing to share her experiences.

5.5.2. B: Hermeneutic Interpretation

The interpretative process began during the conversation but the transcription facilitated further clarification and clear evidence for the construction of significant statements and first level themes. Two areas identified in the first guided conversation are 'Own learning' and 'Relationship - fitting in with the person'. These two first level themes are identified with their significant statements,

Significant Statements supporting First level themes: 'Own learning'

> 'It was a big learning curve with the first case'
>
> 'with interventions, it's the little things that matter'
>
> 'the impact of human vulnerability changing views of caring interventions'

Significant Statements supporting First level themes: 'Relationship'

> 'I change depending on what they're like'
>
> 'Some people are very jolly, making a joke of it all, that's the way they are, you sort of join in with that.'

> 'Other people don't want to talk about it'

Following analysis of the transcription and her receipt of the text, the second conversation was arranged for validation of the initial interpretations.

5.5.3.C: Learning Through Dialogue

The second conversation attempted to determine whether horizons could merge and the extent of differences (see appendix 7a). The interpretations were acceptable to Ann and although there were some adaptations of title between first and second level themes to enrich the meaning there was no discord or areas of confusion (see appendix 10 for listings). My openness to her experiences and values was sound and this reflected how my interpretations were increasingly compatible to the tellers.

5.5.4. D: Thematic Construction

The titles of some second level themes had additional modification when developed into individual categories but their sense remained. In the case of the first level theme 'own learning', this became 'learning to care through experiences' after dialogue (second level theme) with PC7, and 'learning sensitivity through experiences' when an individual category. The other example, 'Relationship- fitting in with the person' changed to 'responding to the patient's demeanour' (second level theme and individual category) and when this was considered in relation to the other individual categories a major category entitled 'Situated Friendship' emerged. Table 13 offers an illustration of the construction from first level themes through to the major categories in these two areas.

Table 13. Ann's themes to categories

First level theme	*Second level theme*	*Individual category*	*Major Category*
Own learning	Learning to care through experiences	Learning sensitivity through experiences	**Learning through experience to care**
First level theme	***Second level theme***	***Individual category***	***Major Category***
Relationship - fitting in with the person	Responding to patient's demeanour	Responding to patient's demeanour	**Situated Friendship**

The final stage was to incorporate all the individual categories into major categories for the group. Appendix 10 lists eight PC major categories with two exemplars offered in table 14.

Even though the professional participants were a diverse group, their similarities were quite apparent as many of their values and approaches to care were similar. The expectation was for greater diversity. However, this outcome appeared to offer exciting possibilities for common features in the development of inter-professional education and practice.

Table 14. Development of PC major group categories

Individual categories	**Major Categories**
PC1 Educational imperatives: helping others learn to be cared for PC2 Openness to learn PC3 Learning through caring PC4 Novice learning about care PC5 Learning through experience PC6 Learning about MND care **PC7 Learning sensitivity through experiences** PC8 Learning through experiences	**Learning through experience to care**
PC2 Holistic stance toward the patient PC3 Responsive friendship PC5 Responsive friendship to meet patients needs **PC7 Responding to patients' demeanour** PC9 Responsive close relationship	**Situated friendship**

5.6. WHEN DOES THE ANALYSIS CONCLUDE?

There is always the question in analysis of when should the analysis process cease? Cormack (1991:300) warns against 'data shuffling'- continually sifting and sorting through the data' but as the analysis was underway, questions were constantly being asked by the researcher, 'is this first level theme robust?', 'should I re-visit these themes, this individual category or major category again?', 'could I interpret this significant statement differently?' The decision to re-visit or remain fast stimulated a reflective stance and all stages of the analysis were visited many times. The researcher chose to stop when the questioning calmed and possibilities felt exhausted. Then confirmability was sought from the two external experts, research supervisors.

Through the second conversation with participants, initial confirmability was expressed by the participants. After this stage had passed, external experts, in terms of the research supervisors, were invited to view and make suggestions concerning the analysis outcomes for verification of the process and its reasonableness to the final construction.

Eventually, as Strauss (1987:280) suggests, the researcher 'has somehow to endure the pain of severance'. This pain can be reduced through the knowledge that diligent examination and re-examination of the evidence has taken place, together with the collaboration of participants and supervisors. This ending therefore usually occurs when avenues have been exhausted, the evidence feels well sifted and sorted and reflective questions can be answered. As no interpretation is ever complete, eventually a stop is appropriate.

5.7. SUMMARY

This chapter has presented the stages of analysis with illustrations from the evidence. It began with the stories from participants and led to the development of major categories for each group. Although only one participant from each group was used for illustrative purposes, the aim of the chapter was to present the analysis process for the reader to appreciate how the interpretative analytical process has been built. Chapters 6-8 offers the group category findings in more detail.

CHAPTER 6: THE MND CARED FOR GROUP FINDINGS

6.1. INTRODUCTION

Presenting findings and conceptual models of a phenomenon in a hermeneutic study raises an interesting tension. If it is accepted that continuous dialectical interchange between text and interpreter through questioning is the vehicle for promoting fusion of horizons, then it follows that meaning is not a fixed entrenchment but is always open to interpretation. In this continuous process, Weinsheimer (1985:211) advises that, 'The interpreter best understands himself as a participant in a continuing conversation, one that pre-dates his own consciousness and will post-date it'. Presentation of any findings therefore does not indicate a final end-point but merely a stage in the conversation.

In this light, the next three chapters present a stage in the conversation. They offer the constructed group categories and the individual group conceptual models of caring from the three participant groups. The group categories are constructed from the individual categories of each participant (see **bold** in figure 5a). The individual categories were constructed from the first and second level themes following the second guided conversation (see chapter 5).

Figure 5a. Diagrammatic representation of analysis process

Action	Stages
Individual story presentation	A. Hearing and Writing the Story
Identify significant statements	B. Hermeneutic interpretation
First level themes	C. Learning through dialogue
Second level themes	D. Construction
Individual categories	↓
Major group categories	
Group conceptual model	E. Conceptual model of phenomenon
	↓
Conceptual framework for lay and professional values of care	

6.1.1. Initial findings related to values

Values are the corner stone of the research question 'What are the lay and professional values of care in the context of motor neurone disease and is there a difference between them which affects care delivery and receipt? In addressing this question, it is important to reflect on the discussion of values located in chapter 2, where distinctions are made between liking or practical and moral or philosophical values (Downie and Telfer 1980). These two essential divisions in values were discussed in conjunction with Blustein's (1991) differentiation between four uses of the word care. These are supportive to the stated practical and philosophical division.

The practical dimension is concerned with practical action whereas the philosophical dimension is concerned with ways of being. Ways of being are influential to practical action. It is possible to be practical about something such as help with mobility problems but make little effort to consider the impact of one's interventions or even how immobility affects the client. This leaves the receiver of care with a practical intervention but with no personal interactive support or acknowledgement of their difficulties.

This practico-philosophical division is upheld for the initial examination of implications arising from each of the constructed categories through the three following chapters. The division is recognised as being a convenient initial classification strategy. However, the developing argument is in favour of its closure or reunion due to the importance of their integration for holistic practice. The professional learning recommendations constructed in chapter 9 present a combined practico-philosophical stance.

In light of the research questions and cognisant of identified differentiation between the practical and philosophical values, the following brief overview of the findings is listed below. Evidence supporting and grounding these claims is presented in this and the next three chapters.

- The three participant groups do have values of care which can be identified within the divisions of practical (liking) and philosophical (moral/ideal) values
- The three participant groups each have their own care value stance which results in three ways of caring

- There are similarities and differences of caring values between the three groups
- The three ways of caring seem to affect aspects of care delivery and receipt
- In addition they exhibit different foci;

- needing care creates vulnerability and loss of control
- being a lay carer creates personal suffering and hard labour
- being a professional carer creates a sense of usefulness and achievement
- professional, practical caring functions usually match the cared for practical needs
- philosophical caring ideals and needs differ across the three groups

- Learning to care/be cared for attracts educational needs within the practical and philosophical delivery areas
- A greater awareness and understanding of the diversity of caring values amongst the three groups should influence care delivery and receipt through gaining 'new knowledge' or 'broadened horizons'
- Although values cannot be imposed on others, appreciation of another's values can be informative to affect practice

These elements are considered in comparative detail in chapter 9. The supportive evidence is located in this and the next two chapters where the group categories are presented with their respective practical and philosophical implications. The main focus of these implications lies in education and practice. First, a summary of the three group categories.

6.1.2. THE THREE GROUP CATEGORIES

These group categories are collectively presented in table 15. The MND participant group consists of nine categories, the lay carer group has ten and the professional carer group has eight categories.

Table 15. The Three Group Categories

MND (9)	LC (10)	PC (8)
Existential shock	De-stabilising impact of impending death of spouse	Strengths of professional role
Importance of creating meaning	Searching for answers	Ideals of care
Struggle with increasing loss of control	Forced life changes in caring for another	Role limitations
Temporal realisations		Situated friendship
Learning to be cared for	Learning through caring	Learning through experience to care
Changing relationships	The vulnerability of being a carer	Critical nature of time
Dynamic normality	Temporal realisations	Importance of inter-professional co-operation
Strengths and limitations of received care	The false normality	
Reality unmasked through reflection	Strengths and limitations of professionals	Continuum of reflective reflective thinking
	Preparing for loss	
	Reflection highlights reality	

The categories are presented with a temporal priority, this reflects the emphasis made by the participant 'tellers'. The first is the highest priority for the telling group. For example, the first category in the MND group is entitled 'Existential shock'.

The MND participants began their stories with tales of their journey towards the diagnosis and the shock they experienced on realising the implications of MND. The lay carers began with examples of the de-stabilising effect of the MND diagnosis (prospect of losing their partner through disability and death). The professional carers began how they help people with MND, by re-counting the strengths of their role in a functional sense.

The evidence illustrating the first two participant group's categories follows and is supported with practical (action) and philosophical implications (ways of being) which reflect the

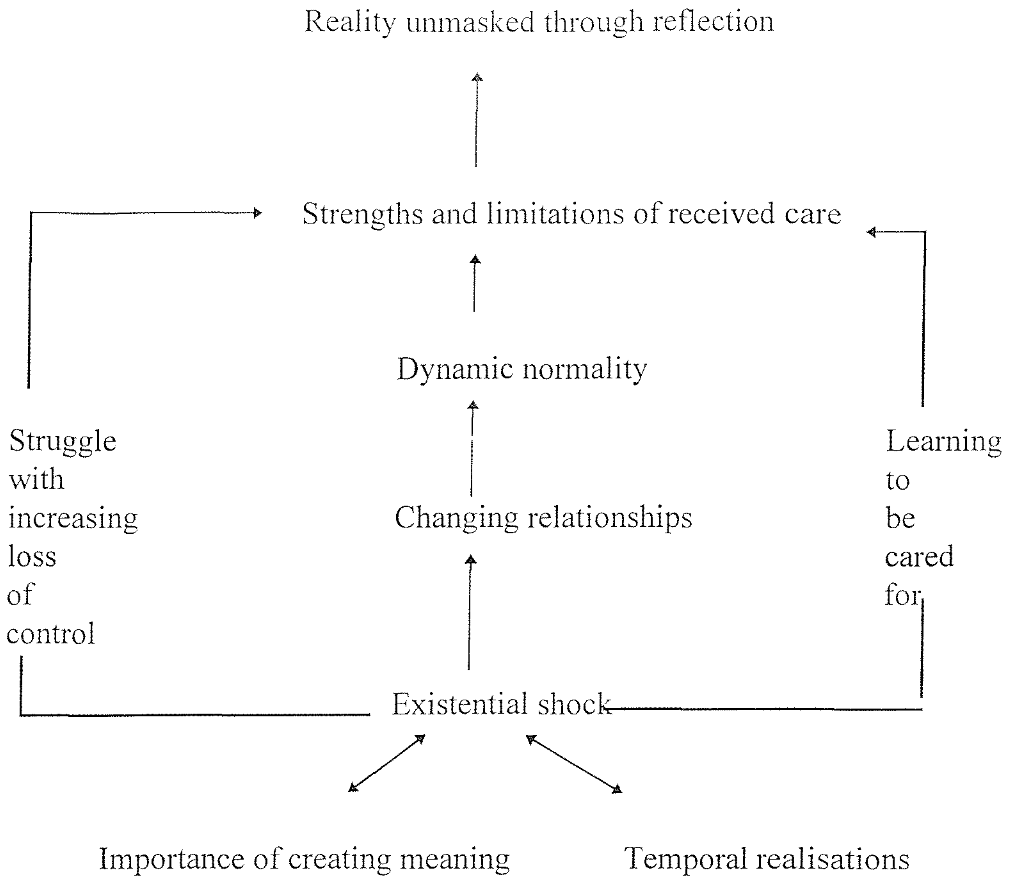
groups' values. This process aims to consider the triad interface of effect and affect for each category and is supportive in building the total picture of the MND care experience.
The remaining group categories are presented in appendix 11. All implications from the three perspectives for each category are illustrated in this chapter.

6.2. FINDINGS FROM THE MND PARTICIPANT GROUP

All nine MND categories have an inter-relationship but are initiated by the first category of 'existential shock'. This category captures their discovery of their symptoms, the telling of the diagnosis and appreciation of its implications. Sequentially their shock is linked to their struggle with the physical constraints the disease imposes upon them. MND participants tried to create meaning out of their situation but temporarily they realised their life and their goals were now limited. They were almost 'bargaining' (Kubler-Ross 1969) for certain goals such as seeing a son married to defer the day of death in order to be allowed to meet a goal.

The MND participants struggled with increasing loss of control in the physical and emotional dimensions. As their 'control' diminished, their needs for caring interventions increased and they had to 'learn' how to be cared for. These two categories, 'struggle' and 'learning' almost work in tandem but in different directions. Inherent in this tension, relationships with their partners changed as the balance of their roles shifted. There was a continual desire to maintain some sense, to create a new normality. The new normality had to be 'dynamic' as their deterioration required pro-active re-adjustment. As the cared for reached out for help from others, they realised the strengths and limitations involved in receiving care. They needed others and received much practical and emotional support but in their extreme situation nobody or anything could reverse their situation. In many instances what they were expecting from others was not forthcoming and so there were disappointments. When they told their stories, dialogue with an 'outsider' highlighted the reality of their situation more acutely. Figure 6 reflects the stories of the MND participant group. Each category is related to the others as they represent the experience of the participants but each is be examined separately at this stage clarify their implications for practice.

Figure 6. Inter-relationship between the MND categories



6.3. EXISTENTIAL SHOCK

Six individual categories were merged to form the group category ‘Existential shock’ as exemplified in the box below. Quotations are taken from original stories to support the construction of this major group category.

MND1 The shock of MND
MND2 Horrors and uncertainty of MND
MND3 Destroyer of life
MND4 Journey through the diagnosis
MND5 Journey to the diagnosis
MND6 The shock of MND

The category ‘Existential shock’ captures the experience of facing one’s imminent death and recognising one’s physical vulnerability but without the knowledge or experience of how to handle such news. Existential shock has echoes of Kubler-Ross’s (1969) category ‘Denial and

Isolation' from her model of death and dying. One participant shares how she dealt with the shock of realising she had MND through denial:

'you knew but you didn't say anything to anyone. You carried the burden alone preferring to protect people and to protect yourself' (MND6)

another adds that the consequence of such behaviour makes one:

'feel lonely and very tired' (MND3)

The journey through the symptoms which led to their realisation of something being wrong varied between them but one man recounted his journey as beginning when:

'I first noticed it in my little finger and then in my hand generally and then my whole arm ..the next symptom [with me] was my voice slurring .. and then it went into my left arm' (MND3).

Securing a diagnosis of MND was difficult and added to the feelings of shock as these two extracts portray:

'it started in my leg and then they told me my voice was slurred....then I got a cold and I was blocked up with catarrh. I saw an ENT specialist who sent me to a neurologist ... he thought it was myasthenia gravis.... I told the neurologist that my arm started aching and after some tests they found something in my thumb. Then I went to the neurologist again and he wanted a second opinion so I went to the National Hospital. It was a terrible year, it had taken a whole year to find out what was wrong with me' (MND4)

'it was the swallowing, I had a funny sort of problem with choking that was the first thing, I went to the doctor and he couldn't answer...I went back as he said 'if it gets worse come back', So after three months I saw him again and he sort of confirmed suspicions' (MND1)

The professional carers in this study all acknowledge how notoriously difficult it is to be certain about a diagnosis of MND. They admitted that if MND is suspected, often the diagnosis is delayed to protect patients from the awful reality.

The evidence in this study suggests from the patients' perspective that not knowing is equally stressful. Many of the symptoms were frightening, such as tripping up over their own feet. One presented with slurred speech which others suspected was secret drinking. These 'unsociable' but unexplained behaviours drove the cared for to seek a reason. There appears an inherent importance to have a disease labelled to allow a certain rite of passage, so it can be privately and publicly acknowledged and they can start developing strategies to manage. As one patient expressed on receiving the diagnosis, her denial was harder to maintain as, 'the door was open and it was real. There it was and now you knew you had to deal with it' (MND5).

On securing a diagnosis, shock deepened in terms of the uncertainty of what to expect next from the disease and of how long life remained,

'it's a bit shattering. First of all you don't know what to expect, it's hard to know what it's all about. So it's a bit of a shock to start with 'cos of course you don't know how it's all going to be' (MND1)

It's 'Horrible, it's the worst thing I can remember. Not knowing how long you've got. Not knowing where you're going, how you are going to be and not having any guidelines' (MND2).

The knowing reduced some uncertainties but created space for more. The course of MND for each individual is uncertain in terms of muscle area deterioration and over the time scale. The patients knew every 'case' was unique and that the professionals were unable to state causes, outcomes and time frames. This reality made the disease harder to fight against as these participants explain;

'when they say they don't know what causes something you've got no goal to fight against... it's very hard to fight against something when you don't know what you're fighting against' (MND2)

'Not knowing is quite annoying ... knowing is better than the fear of the unknown' (MND3)

However, the confirmation of the diagnosis was equally shocking. The uncertainty of their symptoms made them 'very frightened' (MND3). Five offered negative comments about their consultant's approach to them. They complained the act of confirmation was insensitively handled. The MND participants accepted the consultants were very knowledgeable about neurology but possessed no 'people skills' or 'bedside manner' which diminished their future confidence and expectations from professionals.

These descriptions explain,

'he's a brilliant man though his communication skills are bad, zilch. He just said 'You've got motor neurone disease and three to six years to live' and left' (MND6)

'I found him difficult to talk to. I didn't find him very sympathetic. I found his answers arrogant, as though I wouldn't understand what he was talking about, when really his job is to explain to me so I can understand' (MND2)

The 'existential shock' rippled throughout the remainder of their lives. Living with death and suffering created a very stressful situation but encouraged them to try to live for the moment. Realisation of the vulnerability of being human also bought a greater depth of thought in relation to one's mortality, one participant acknowledged this;

'I managed to think about dying...I know I'm going to die and I value every month much more... life means more, I know that within a very short frame of time I will almost certainly die and that I am not sure that a lot of people wonder about that until the moment they die...'.(MND3)

This thinking cannot sustain a person in the life they have yet to live, however as Kubler-Ross (1969:52) writes, 'patients can consider the possibility of their own death for a while but then have to put this consideration away in order to pursue life'. Pursuing life was to 'Struggle with their increasing loss of control' as exemplified in the next category. First, implications arising from 'existential shock are considered.

6.3.1. Implications of category 'Existential shock'

'Existential shock' encapsulates how MND patients are confronted with their symptoms and ultimate diagnosis to realise they are going to die (within 3 months to 3 years), whilst witnessing their bodily functions decline in an uncertain manner. MND patients realise their human vulnerability and value this being respected by others. In practical and philosophical (ways of being) implications, the following are identified;

***Practical implications*:**

A: Cared for

- need for a diagnosis to explain symptoms
- need for early referral to a range of professional agencies to reassure them practical help is available
- need for early contact potential with the voluntary agency, MNDA

B: Lay Carers

- need for practical help to support their spouses with this shock - someone to talk with spouse, key worker to set up physical services
- need help themselves to cope with this shock - someone to talk with them in addition to their partner

C: Professional Carers

- need for a clear protocol for searching/telling the diagnosis of MND
- need to plan timing when telling the diagnosis to allow for emotional support to be available (e.g. relative)
- educational support to help them offer news of MND sensitively
- need to develop strategies to offer support to patients/lay carers during and after the telling
- need to promote continuity of experienced and interested care professionals who can be with the patient throughout the disease trajectory

Philosophical implications for ways of 'being'

A: Cared For

- need for a sensitive teller of the diagnosis
- reassurance that being vulnerable and frightened is 'normal'
- need for patients and others to understand the 'existential shock' concept and the 'situatedness' of the person newly diagnosed with MND
- need for others to help share the shock its impact
- if something is needed to 'fight against', then the early presence of a professional can help to offer a sense of achievement in their physical challenges

B: Lay Carers

- appreciation by them and of others that the threat of MND creates
- acknowledgement of their partner's shock, its effects and the prospect of an early death
- acknowledgement of their own possible shock, its effects and the prospect of being alone

C: Professional carers

- no acknowledgement of existential shock, is effects coupled with the prospect of an early death
- no sense of sensitivity of engaging with a 'dying' patient and his or her family
- need to increase understanding about the impact of such a diagnosis on a person's life
- systems to be developed to promote continuity of experienced and interested care professionals who can be with the patient throughout the disease

6.4. IMPORTANCE OF CREATING MEANING

MND1 Knowledge adds meaning
MND2 Information and experiential knowing
MND3 Searching for reasons and meaning
MND4 Searching for information and meaning
MND6 Search for meaning from suffering

The importance of creating meaning revealed four main searches; for knowledge about MND to make meaning out of the symptoms, for what may happen to them in the course of the disease so they could anticipate the next stage; for why they contracted the disease in the first place; and why should there be suffering such as this in the world. These searches gave people a task and in this task of seeking explanations, even if none were forthcoming, led them to some discoveries and making meaning.

A common response to living with MND was how 'life means more' (MND3), the meaning of life being enhanced through the imminence of death. This has echoes of Potter's (1994) 'nowness' of life, realised when it's very existence is threatened. Questions as to the meaning of life demanded information from a variety of sources. Many people turned to the health literature to read all they could about MND.

Some attended the local MNDA meetings to talk to others, trying to see if they could establish any causative common denominators, even though they knew the cause was 'officially' unknown. Others sought explanations from the professional carers. As MND leaves the intellect intact it seemed that people dwelled in this cognitive domain as their physical side deteriorated. The following extract is from a participant talking about the contribution of the speech therapist's knowledge in helping to create meaning of his symptoms;

'It's not so much [what] they can do in the practical sense but they're very supportive and they know what the problems are. They can explain why I am having trouble swallowing and speaking. If I didn't have them [speech therapists], I wouldn't realise what the problems are and it's worse when it is happening to you ....when people say well, that's what we could usually expect, it's caused by this, that's very helpful because you worry about things' (MND1)

Health professionals offered clients explanatory information from their various fields of expertise. However, the MNDA voluntary visitors offered most comfort and reliability. They all had experience of relatives or friends who had died from MND, they knew the range of equipment which could be needed and could estimate the speed of progression. They had experiential knowledge of the suffering and shared this knowledge with the current victims through their presence and words of reassurance. MNDA local meetings aimed to support people to feel they were not alone, 'as far as I'm concerned seeing others, you know you' re not the only one.. going to the meetings has been very supportive' (MND1). However, others could not attend such meetings as they did not want to be surrounded by ill people 'I want to be with normal people' (MND6) and others wanted respite from the reality, 'I don't want to face it all the time' (MND4).

One participant did not contribute an individual category towards 'creating meaning'. MND5 was a lady towards the end of her life who had already resigned herself to dying of something. She implicitly had made meaning out of nature's course. By contrast, MND6 wanted to be active in creating meaning out of her suffering and took control so 'some good must come out of all this bad'. She had made legal moves to donate her body to medical research. Participating in this study was an opportunity for MND participants to create meaning out of their situation. It offered them the opportunity to be heard and to leave a trail, to leave the world something about them and their critical situation, for themselves and a possible future benefit.

A sense of meaning in any dimension cannot detract from the inevitable disease process or its conclusion. There came a time when sufficient exploration of meaning had been achieved and was no longer sought. MND4 came to this situation quite early as she refused a second conversation with me and just wanted to live rather than think or talk about it any more. It was too painful and too real to confront anymore. Even on the first conversation she talked about being 'resigned' (MND4) to it all... 'I mean what's the point of going over and over it.... talking about it makes me feel weepy'.

The physical meaning was gained through appreciation of disease process. The emotional, existential approach to meaning was too uncertain, too painful so ultimately resignation became the only option. MND3 had been voracious in his initial explorations and discussions about MND with his wife but on the second conversation admitted, 'I think we talked about it a lot and you're wondering whether perhaps now you're talking about it too much... I think we have talked about it too much. It worries me whether we have said too much' (MND3). The harsh reality gained from all the initial talking concluded that there is no solution, no escape.

What was left was learning how to suffer, how to live with the anticipation of dying without absolute answers. This resulted in generating meaning through the people they had in their lives. Those who declared a reason to live, an attentive, loving family members such as children (MND2,3,4), a strong martial relationship (MND3,4,5,) or a good friend (MND6) seemed to have more meaning to want to continue living. Those with looser bonds (MND1) did not exhibit such desires. Perhaps the ultimate meaning being sought was not of the disease but of themselves and was found in love and being loved which was exchanged in care and being cared for. Technical knowledge may offer answers to technical questions but human knowledge and experiences, when distilled, appear to lie in human relationships.

6.4.1. Implications of category 'Importance of creating meaning'

Creating meaning out of disease and suffering is on two levels: first through learning technical information about the disease and its effects and second to address the human question of 'why?' The technical level can be assuaged through literature and explanations where knowledge is known. The human meaning is more complex and may not be resolved but acceptance can be gained through personal perspectives of human relationships.

Practical implications

A: Cared For

- there is a need for available literature and information on MND to be readily available for people diagnosed with MND, to include its possible causes, trajectories, treatments, sources of help and interventions
- there is a need for people to have opportunities to talk through this type of information with professionals and lay members of agencies such as the MNDA

B: Lay Carers

- seeking meaning is a human trait and requires support rather than opposition
- technical information can be sought through professional and volunteer agencies
- human meaning is a complex construction and takes time to construct

C: Professional Carers

- questioning from patients is part of their quest to create meaning and should be responded to with sensitivity and honesty
- making meaning can be helped through clear, careful and accurate technical information.
- there is a strong role for care professionals to explain aspects of their work to patients and lay carers and to ensure that understanding is achieved to facilitate areas of meaning to be made

Philosophical implications

A: Cared For

- we need to make meaning for ourselves although it is influenced by our histories, prejudices and information gained
- seeking meaning is a common human trait
- love and relationship are vital components of meaning in human lives

B: Lay Carers

- seeking meaning is a common human trait
- one's values influence personal meaning construction but discussion with others may assist its development (MNDA volunteer, chaplin, doctor, friends, loved ones)

C: Professional Carers

- meaning needs to come from the patients themselves, as professionals one cannot make it for them although communication can be supportive in this area

6.5. STRUGGLE WITH INCREASING LOSS OF CONTROL

This category highlights the practical concerns and emotional realities of struggling with increasing debilitation. Loss of control pervades all aspects of their lives. Personal knowledge of bodily deterioration and a loss of physical control forces a person to struggle with facing death and day to day life. They try to maintain a sense of self through clutching to aspects of personal control in difficult circumstances. The six contributing categories are;

MND1 Forced life changes
MND2 Knowing deterioration
MND3 Need for a sense of control
MND4 Constraints on life
MND5 Struggle for personal control
MND6 Loss and struggle for some control

6.5.1. Implications of category 'Struggle with increasing loss of control'

Memories of pre-MND life are their base-lines for judging the pace and extent of their deterioration. Declining bodily function reflects the proximity of death. Remaining in the fight requires energy and becomes their focus. Consciously moving towards death whilst losing bodily control involves a negative sense of 'becoming', a slow loss of 'Being' in all its sense. Appreciation of this struggle is imperative for delivering quality supportive care.

Practical implications

A: Cared For

- need for functional support as their own bodily control diminishes.
- loss of control is a need in itself and so strategies which promote self-control such as active decision-taking and choice are imperative for the sense of self

B: Lay Carers

- acceptance that loss of functional control is inevitable, undesired but essentially uncontrollable
- their work load and responsibilities increase directly to match their partners loss of function

C: Professional Carers

- setting up a team of professionals who can help with functional needs removes duplication
- consideration of extra workload of partner who may require their own assessment of need, both physical and psychological

Philosophical implications

A: Cared For

- implications are rooted in their loss of 'Being'. As the integrity of the bodily self diminishes the mental self suffers alongside. They are losing function and self-control. These losses are a threat to one's sense of worth and social interaction which may result in isolation, loneliness, frustration and despair
- an other is needed to share these losses with them, to listen, interact and demonstrate to them that they remain human beings and are valued as when they were fully functional
- need for sensitivity from professionals who are supporting them in physical losses

B: Lay Carer

- the struggle also affects them; emotional pressure to increase as they see their partner deteriorate and struggle and they are pulled into the emotional angst as well as exhaustion in offering physical and emotional support

C: Professional Carer

- need for awareness of the holistic loss of 'Being', the threat to the integrity of the 'self'
- need to promote choice and control in planning to the support mental self of the person with MND

6.6. TEMPORAL REALISATIONS

One participant aligned her body to a clock, 'Everything I do makes me feel tired. I feel like a clock that's running down (MND2)'. Time is central to her thoughts with the slowing down of her body seen as a mechanical tiredness, the symptom of coping with the physical and emotional distress. Being in time is her acute experiential reality which creates the category of 'temporal realisations'.

MND1 Time closing in
MND2 Importance of given time and goals
MND3 Living for the moment in time
MND5 Parcelling time
MND6 Time and goals

6.6.1. Implications of category 'Temporal realisations'

The MND participants have an acute awareness of the preciousness of time. This is linked to a sharp re-focusing of goals as to what was important to them to sustain hope and reduce their suffering. There is evidence of bargaining with life which firmly locates these people on the death and dying trajectory as well as in disability. Goal setting can be viewed as a way of caring for themselves. Any achievements can contribute to dealing with the suffering, sadness or depression by seemingly taking control over their life.

Practical implications

A: Cared For

- the realisation of time running out stimulates a rapid assessment of what is important to complete before departure
- people with MND need to be supported to remain functional for as long as possible to strive to achieve their stated goals
- spoken goals offer a target for them and others to work towards and re-establish a sense of hope and personal control

B: Lay Carers

- need to expect the possibility of goals being presented to them from their partner.
- goals ideally can be encouraged to be realistic to their possible time frame. (Some goals may have direct effects on their lay carer who may be asked to pursue the goal as a proxy if it is not completed before their death)

C: Professional Carers

- need for awareness of the possibility of goals being set by patients
- consideration of the pressure the goals may place on the lay carer
- efforts to physically support the patient to achieve their goals with realisation of the critical nature of time for these people

Philosophical implications

A: Cared For

- are located in their sense of hope. Achievement of goals or the planning of goals can be for preparatory closure and 'letting go'
- are linked to the process of dying, incorporating shock, anger, bargaining and suffering through impending loss. Such loss is of function, self and Being. They are about to lose everything and their goals can serve as a gain in this equation
- interest and support in a person can stimulate goals and hope which may be linked to time span

B: Lay Carers

- taking an interest and supporting their partner can stimulate goals and hope, which may be linked to time span

C: Professional Carers

- recognition and support for goals as being a vehicle for patients to re-gain a sense of control and hope, which may be linked to time span

6.7. LEARNING TO BE CARED FOR

At first sight it may be considered unusual that one has to learn how to be cared for. This category captures the acute change in circumstances MND creates for people as they have to learn new skills and a new way of Being.

Learning to be cared for involved a transformation of 'Being'. They had to learn 'how' to receive care in the physical sense and the psychological sense of learning 'gratitude and tolerance' towards others for attending to their vulnerability and passivity. They had to learn much about loss in terms of their rights and independence.

MND1 Adjusting to being cared for
MND2 Learning how to be cared for
MND3 Learning gratitude and tolerance
MND4 Learning acceptance of loss and gain
MND5 Learning to cope with caring
MND6 Frustrations in needing care

6.7.1. Implications of category 'Learning to be cared for'

The MND participants did not like being cared for as it involves loss of privacy. The need for caring emphases one's vulnerability and loss of control. Being cared for requires expressions of gratitude and tolerance even when they are resisting their situation but these 'learned ways of being' are to promote the social/professional carers to continue which removes pressures from their partners. Learning to accept care is a struggle that can be linked to accepting the disease and its implications

Practical implications

A: Cared For

- being cared for is disliked. A continual tension in this area can create more exhaustion and frustration
- accepting the disease and therefore the caring may need time
- adjustments will need to be made to many practical aspects of life and these need to be considered, debated and when possible agreed with the recipient
- appropriate action made with choice remaining with the cared for, for as long as possible
- consistency of all carers is desired
- awareness of the pressures on lay carers, as caring is hard work may promote acceptance of other carers
- communication difficulties exacerbate feelings of vulnerability and make acceptance of caring harder, particularly if carers change

B: Lay Carers

- resistance to social carers may be worse if personnel changes are frequent
- 'supervision' by lay carers of contact with social/professional carers may be supportive for partners who have communication difficulties
- emotional frustrations may be met with increasing loss of independence by their partner
- the link between accepting the disease and caring may need time

C: Professional Carers

- patients experience anxieties concerning challenges to privacy, this needs effort to reduce these challenges
- promote continuity of care at all times - team approach important
- when there are communication challenges, always speak to the patient but involve the lay carer to help interpret so the cared for is always heard
- lay carers need support with practical interventions of learning care, in addition to the patient

Philosophical implications

A: Cared For

- accepting care may be linked with accepting MND
- knowledge that adjusting and learning to care are 'normal' features of having a disabling disease may help in this phase of a change of 'being'
- challenges to privacy can be debated with carers to develop strategies to minimise them
- vulnerability and loss of control are inevitable outcomes of being cared for; they are a shift in one's state of being
- awareness of the stress on partners in caring is important but this needs to be balanced with the patient's need to preserve their 'voice'
- communication difficulties can render patients more out of control and vulnerable as they cannot express themselves. In preparation for this and to reduce these

feelings, set up a written introduction of yourself, your preferences and dislikes in many situations for a range of audiences

B: Lay carers

- awareness that partners acceptance of care may be linked with accepting their disease
- the stress of caring for a partner may be enhanced if they resist your interventions. Need to discuss the ways of being patients prefer
- need for awareness and sensitivity of partner's anxiety concerning challenges to privacy and dignity with effort made to reduce these challenges
- as communication difficulties become more profound partners may withdraw. Need to plan future communication strategies
- awareness that more social isolation occurs as patient communication decreases

C: Professional carers

- need awareness that for patients to accept care, this may be linked with accepting their disease
- need awareness that patients are being forced to learn how to be cared for. It is a threat to them and disliked (if they react against it, it is not necessarily personal)
- lay carers will be exhausted by the effort of caring and have their own needs
- communication challenges do not remove the person from the caring focus

6.8. CHANGING RELATIONSHIPS

The previous category clarifies how the need for caring creates role changes between partners, in caring the dynamics of a relationship change. These changes can create problems as well as offer areas of strength.

MND1 Relationship role shifts
MND2 Relationship problems
MND3 Changes in relationships
MND4 Strength from purpose
MND5 Abstention from role
MND6 Diminished role

6.8.1. Implications of category 'Changing relationships'

MND hijacks the person; their roles, relationships and ultimately their way of Being in the world. Through witnessing their own physical deterioration and communicative isolation their roles diminish and their relationships shift with others and themselves. This leaves the person with MND almost in a state of 'anomie', with no future prospects but death. They are dying as are parts of their relationships with others. Their role shifts and abstentions are rehearsals for their permanent absence. The feeling and reality of 'being cut off from life' seems to be the pivot of changing relationships.

Letting go roles can result in relinquishing relationships. As one finds the roles which defined you are no longer yours there is a loss of original self. The loss of original self makes you into a different being and the practical and emotional relationships with others can become unbalanced. This creates a dual problem, loss of self and potential increased isolation from others. The result can be a lonely useless existence whilst waiting to die.

Practical implications

A: Cared For

- relationships are naturally dynamic at the best of times and usually involve a give-and -take premise. Where the give reduces in some areas, it may be possible to increase it on others - more thinking strategies than doing strategies
- promoting the continuance of previous roles when at all possible reduces the impact of the physical deterioration on the self.
- the loss of ability to fulfil roles eventually means the roles need to continued by someone else: perhaps if this is achieved through negotiation it can be a little more manageable for them
- clear transference of responsibilities may offer a relief for the carer and a sense of purpose and worth for the cared for

B: Lay Carers

- as the partner's ability to perform roles diminishes, this places more demands on the carer in household responsibilities which might mean more external help is required and new skills need to be learnt

C: Professional Carers

- knowledge of the role and relationships before onset of disease need to be known to appreciate the stressors the person with MND and their partner are undergoing
- changing relationships may affect care delivery by lay carer to spouse and mean more external support is required

Philosophical implications

A: Cared For

- loss of role is linked with loss of self which changes the dynamic of relationship
- loss of 'self' through altered definition of role is linked with potential loss of life and preparing to leave the relationship through death
- the threat to one's Being as previously defined needs help to remain in the world - the human being could be lost without a valuation of the person who still is
- relationship counselling may be one route to examining the psychological and emotional interplay in this disease between self, partner and others in the coming to death

B: Lay carer

- changing relationships means a new way of being for the lay carer who also has to plan for a future without their partner

C: Professional Carer

- there seems little awareness of the effects of MND on the sense of self and therefore changing relationships between LC and PC
- psychotherapy or marriage counselling agencies may be supportive for engaging with the sense of their changing selves and hence their changing relationships

6.9. DYNAMIC NORMALITY

This major category encapsulates five individual contributions concerned with re-establishing a sense of normality. It can be aligned to the need for 'homeostasis' in order to re-group, take stock, and try to live some life as well as witnessing its demise.

MND1 False normality
MND2 Re-establishing a normality
MND3 Pretence of normality
MND4 Need for a normality
MND6 Struggle for normality

6.9.1. Implications of category 'Dynamic normality'

The sense of the normal seems to fill a need for emotional rest from the traumas of reality, to replenish reserves for dealing with the anticipatory fear of the future. Although there are no remissions in MND, there can be weeks of stability when some strands of normality can be gained. Normality strategies can be activated before further deterioration and the search for a further sense of the 'normal'.

Practical implications

A: Cared For

- a sense of the 'normal' is related to familiarity to the situation and perhaps an element of feeling slightly in control again
- to help promote a sense of the normal, avoidance of crisis would be supportive
- maintenance of personal routine and when necessary the speedily development of a modified routine

B: Lay Carers

- awareness of need for a sense of the normal is important
- creating a sense of the normal can only be achieved with the co-operation of the lay carers and family

- close co-operation with their partners and the professional carers to discuss actual and potential problems should support this finding

C: Professional Carers

- recognition of this need should support its development
- interventions to support a feeling of safety and relief from immediate danger could be promoted to support this category finding.
- predicting changes in the person's condition should avoid periods of crisis (early feeding tubes, supply of essential equipment) and promote an early return to a sense of normality

Philosophical implications

A: Cared For

- being 'normal' is valued for its sense of stability, reduction of fear and continuance of life and therefore helpful for a sense of well-being
- as bodily changes occur, the attitudes of others should accommodate such changes rather than look shocked

B: Lay Carers

- promotion of a sense of control for the cared for may support the development of being normal
- knowing the new normal and adapting with it is essential

C: Professional Carers

- a calm, confident approach to the family with a measure should assist in this need
- as bodily changes occur, the attitudes others should accommodate such changes rather than look shocked
- promotion of a sense of control for the cared for may support the development of being normal
- knowing the new normal and adapting with it is essential

6.10. STRENGTHS AND LIMITATIONS OF RECEIVED CARE

From the starting point of their 'existential shock', and subsequent involvement with care professionals, MND participants developed their own conclusions about receiving care. This category encapsulates their ideas of 'strengths and limitations of received care'. The strengths are identified as three main sections; functional interventions, demeanour and qualities of carers, situated friendship. The limitations are lack of continuity of carer and lack of emotional care.

MND 1/4/5/6 Limitations of others help
MND 2 Knowing others for support
MND 3 Knowing others for support
MND 5 Need for others
MND 5 Identification of criteria for 'good carers'
MND 6 Criteria needed for caring

6.10.1. Implications of category 'Strengths and limitations of received care'

In terms of receiving functional help, this seems to be forthcoming and competently executed by the care professionals. If continuity of care is possible, this promotes knowing between carer and cared for, which is desired. Such 'knowing' then allows the development of a 'situated friendship' whereby the focus remains on the patient and care is received from a person with an interested demeanour with qualities of listening and being cheerful. Care delivered from a position of strength therefore requires two ways of professional knowing; knowing their functional role and the patient as a person.

A combination of the two ways of knowing reduces limitations in care and extends possibilities. However, the most significant barrier for professionals to actualise the situated friendship approach appears to be the neglect of knowing the patient as a person coupled with no desire to engage with the suffering of these patients.

Practical implications

A: Cared For

- practical interventions through functional support are valued for promoting independence or offering supportive measures
- continuity of professional personnel is a strength as it offers the opportunity for 'knowing' between carer and cared for
- qualities of professional carers competence, active listening and attentive skills, cheerfulness, trustworthy, an instiller of confidence, a sense of being involved
- limited emotional support from professionals can leave the cared for with no emotional care

B: Lay Carers

- practical functional interventions also assists lay carers in their activities
- continuity of professional carers would allow lay carers to develop a relationship with them

C: Professional Carers

- functional care is judged satisfactorily by the cared for but could be rather fragmented
- continuity of personnel is important, particularly as time is often short for the professional carers in their visits
- the amount of emotional support is perceived as minimal which may mean a counselling or psychotherapy professional is required to help people with MND

Philosophical implications

A: Cared For

- knowing one another in a caring relationship is a vital ingredient of feeling cared for, it instils confidence and trust.

- a sense of worth and being valued is promoting by receiving active and attentive listening
- the cared for identify how Being and doing need to inform each other in human interactions
- suffering and loneliness are not addressed by an explicit care professional and expose a value that is unattended in receipt of care

B: Lay Carers

- knowing the professional carers may also enhance their feeling of worth in the caring situation

C: Professional Carers

- as suffering and loneliness are not addressed by an explicit care professional, it begs the question of 'can holistic care be possible from the current organisation and role function of care professionals?'
- knowing patients requires a level of involvement with the focus always remaining with the patient - 'situated friendship'
- professionals need support themselves to offer such relationships to their clients
- question as to whether professional carers want to go this far in a relationship

6.11. REALITY UNMASKED THROUGH REFLECTION

The MND participants suggested that talking about and reflecting on their situation unmasked their reality. As the researcher, I was in a privileged position as a listener, as they reflected on their lives in the world of caring. The guided conversations, once transcribed and interpreted, allowed their experiences to be the mainstay of the findings. Although the guided conversations were not intended as therapeutic outlets, the majority of participants expressed such an appreciation. It was received as an emotional interest and support, which links to the previous category, where they highlight a deficit in emotional support and personal interest.

MND1 Talking promotes reflection and reflexivity
MND2 Reflection clarifies situation
MND3 Useful exercise
MND4 Reflection exposes reality
MND5 Reflection promotes thought
MND6 Reflection raises awareness

6.11.1. Implications of category 'Reality unmasked through reflection'

Talking to a 'stranger' about their experiences with MND was viewed positively with only one participant finding the experience too painful. The positive aspects were related to gaining clarity of thought, being listened to and having the chance to explore their experiences of MND, being cared for and feeling they were contributing to the advancement of understanding about MND. The implications are only considered from the view of the cared for in this category as it is a personal perspective. However, the lay and professional carers had similar attributes in terms of reflection, where it supported the majority but the minority found it too uncomfortable.

Practical implications

Cared For

- talking about their experience can assist in clarity of thought
- talking about their experiences can be distressing and should be stopped if this is the case
- using strangers reduces their responsibility of affecting someone else with their problems
- awareness of the effects of talking about their situation may be unknown to the participants before beginning

Philosophical implications

Cared For

- sharing the burden of 'being-in-extremis' with another can lighten the burden
- finding ways of being not realised before discussion can be positive or negative
- offering a vehicle of talking about their experience confirms their sense of being and making a contribution to others

6.12. MND VALUE OF CARE MODEL

Constructing a model of caring from the findings of the participants with MND needs to be located around their stated central value, the need to be valued and be treated as 'Being human'. The physical deterioration and loss of personal control caused by MND forces people to adapt to a new way of being, that of learning to be cared for through their increasing disability and learning to face certain death in an uncertain time frame. Relational values come to the fore in expression of their humanness, relations with their world, self, time, goals, partners, friends and professional carers. Integrated with their value of being human is the need for expression of their humanness through others; searching for meaning, needing a stable social existence, awareness of temporal issues, ability to learn and adapt to new experiences and situations, awareness of strengths and limitations in self, others and situations

The concept of being human is severely threatened with MND. It steals one's mobility, speech, bulbar function and general independence; all feature of being human. The only element it does not steal is cognition but this can be rendered externally latent through the communication deficit.

The presented MND value of care model (Figures 7 and 8) consists of three parts, all governed by the central value of being human as advocated by Heidegger (Leonard 1994:45). It expresses life before MND and after MND and offers how the transition of circumstance reveals values of care 'in-extremis'.

Figure 7. MND value of care model (part I)

Stable Central Value of
BEING HUMAN

HEIDEGGER'S 'BEING HUMAN' CRITERIA	**Pre-MND**	**Effects of MND**
Having a world	unreflective 'throwness'	reflective 'throwness'
Things have significance and value	situation and context known	new unknown situation and context
Self-interpreting	long heritage context	illness heritage is one of de-valuing persons
Embodiment	centre for all experience	loss of integrity of self
In time	One's horizon of being, past, present, future	past, present uncertain lack of future

TRANSITION REVEALS VALUES OF CARE IN EXTREMIS

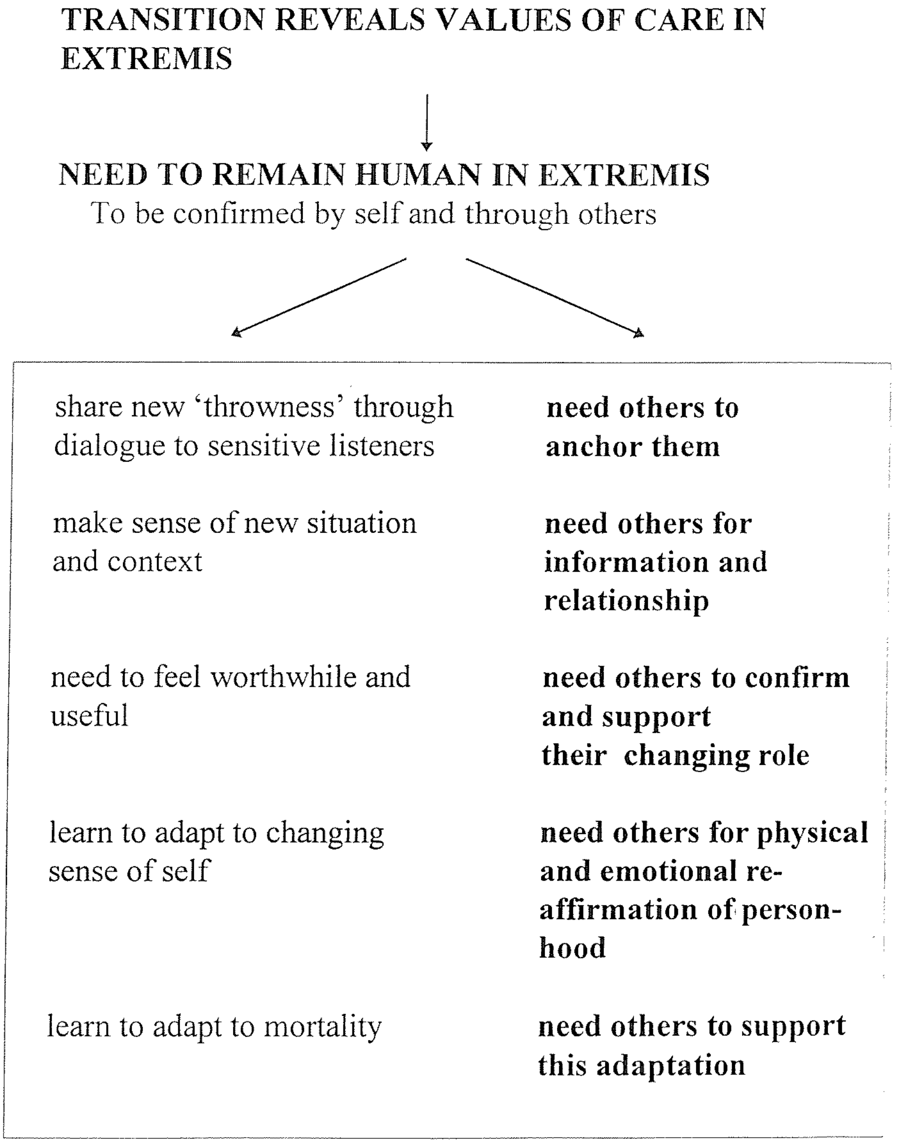
↓

NEED TO REMAIN HUMAN IN EXTREMIS
To be confirmed by self and through others

The value of being human is caring for oneself through one's interpretation of one's world. Once this world changes, as in the diagnosis of a life threatening disabling disease, one's personal interpretation and construction has to change. In a situation involving physical deterioration, it is extremely difficult to do this alone. Others are necessary to support the adaptation. Where this support/care is offered, adaptation can occur and life can continue. When this support/care is not available, adaptation may not be possible.

However, as the evidence in this chapter suggests, the care required is not always delivered. Lay carers recognise gaps in their delivery of care lies in their lack of practical knowledge, physical skills and personal resources. Professional carers have gaps in their emotional and personal resources in addition to the external organisational strategies. The cared for have gaps in their capacity to adapt. Figure 8 offers the second part of the MND value of care model involving the transition from life prior to MND and with MND.

Figure 8. MND value of care model (part II)



TRANSITION REVEALS VALUES OF CARE IN EXTREMIS

NEED TO REMAIN HUMAN IN EXTREMIS
To be confirmed by self and through others

share new ‘throwness’ through dialogue to sensitive listeners	**need others to anchor them**
make sense of new situation and context	**need others for information and relationship**
need to feel worthwhile and useful	**need others to confirm and support their changing role**
learn to adapt to changing sense of self	**need others for physical and emotional re-affirmation of person-hood**
learn to adapt to mortality	**need others to support this adaptation**

The stable value is wishing to remain human, in the Heideggerian sense, despite an extreme change of circumstances. The values of care in extremis reveal the need for personal adaptation but also the greater need for others to care/support them. An absence of this care/support makes life more difficult for the person with MND as their personal reserves are depleted physically and emotionally.

'Being' is about having the necessary bodily functions in order to be. Learning to be without all of one's physical functions changes the nature of being. This change in the holistic sense of the nature of being is the extreme challenge created for people with MND.
Care from others in its best sense is the pursuit of interacting with a whole person, even though there are physical deficits. No one professional group has holistic care as its actual focus, engaging with the MND patient's deeper needs associated with their suffering as well as any physical aspects. Individual professional carers may well appreciate this tension. They may have ideals and professional rhetoric for 'holistic' care. However, the reality of professional pressures is that organisational structures do not support such ideals. The functional emphasis of their professional roles takes dominance over the philosophical or emotional care.

Lay carers have deficits in their functional skills but in the main still see the holistic person of their spouse, unless communication deficits render them unable to see the person. Lay carers who love their partners are in the strongest position to offer 'holistic care' but problems arise if lay carers are not motivated through love or have deficits in their own personal resources. This can lead them to withdrawal from the 'disabled' person, as they no longer recognise them as their partner.

6.13. SUMMARY OF CHAPTER

This chapter has presented findings from the six MND participants. Textual illustrations are offered to support the constructed categories and two 'models' have been offered. The first model highlights the temporal relationship between the categories in terms of how the MND participants' journeyed through their extreme situations. The second model is structured around the central caring value of the cared for, the need to be valued as a human being, by themselves and through the care of others.

CHAPTER 7: THE LAY CARER GROUP FINDINGS

7.1. INTRODUCTION

This chapter presents the findings from the lay carer participants. Ten categories are constructed which illustrate the lay carers' journeys through the world of motor neurone disease. Parallels can be drawn with the experiences of the MND participants, although there are additional features, ('vulnerability of carers' and 'preparing for loss'). The first two categories are presented in full. Thereafter only the implications with the full evidence located in appendix 12.

The starting point for the lay carers is their response to their partner's diagnosis. Its implications result in the 'de-stabilising impact of impending death of spouse'(see table 16). This reaction has similarities to their partner's 'existential shock'. The lives of the lay carers are suddenly transformed; the implications are realised in terms of the required skills, effort and time it takes to care for another. This is coupled with the potential loss of their partner's life within an unknown time frame. The de-stabilising focus initiates their search for answers as to why this disease should have struck and what is the nature of the disease that they have to watch kill their partner. As MND progresses, the lay carer increasingly has to act for their partner in many areas. The lay carer responds to a change in circumstance where they are no longer the wife or husband but an essential resource in supporting the other's life.

Table 16. Ten categories from LC participants in temporal priority

1. De-stabilising impact of impending death of spouse
2. Searching for answers
3. Forced life changes in caring for another
4. Learning through caring
5. The vulnerability of carers
6. Temporal realisations
7. The false normality
8. Strengths and limitations of professionals
9. Preparing for loss
10. Reflection highlights reality

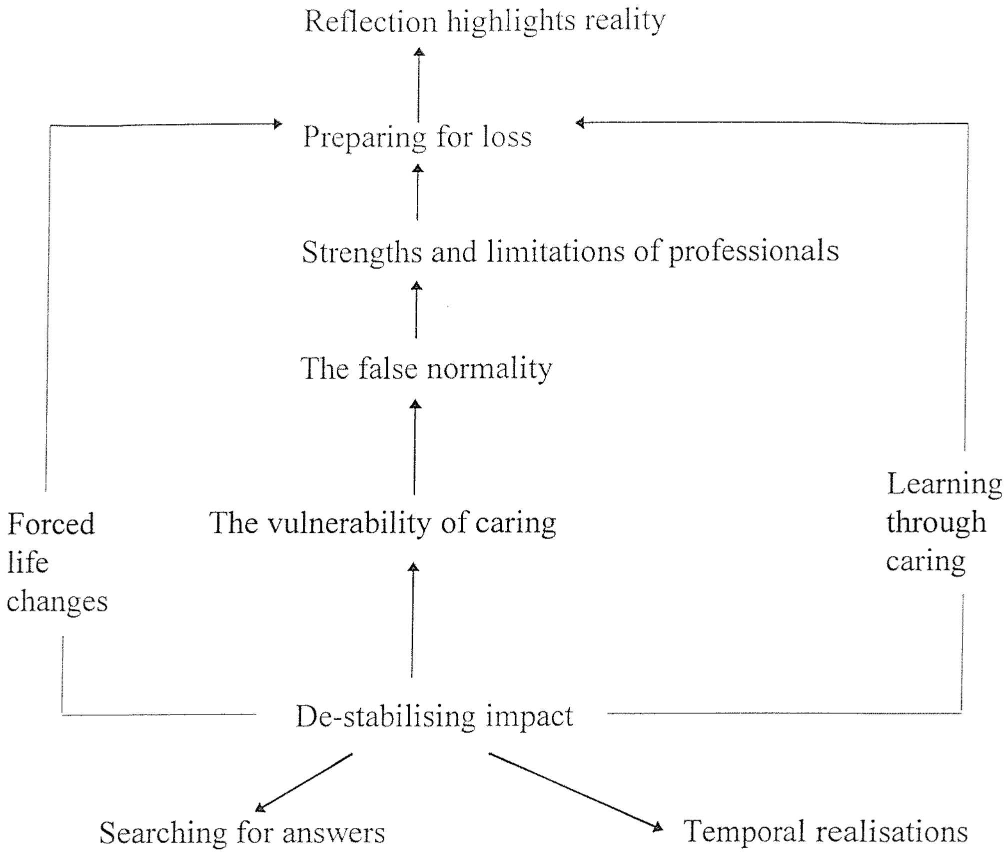
The lay carers experience 'forced life changes' to respond to the needs of their partner. These changes increase in parallel with their 'learning through caring'. Lay carers are challenged emotionally and physically in their delivery of care which highlights their own need for care. Caring is perceived as hard work, a full time job, emotionally exacting, with no relief to regenerate them, no escape from the continuous deterioration, only anticipation of their partner's death. Lay carers recognise their learning needs for coping with the physical aspects of care as well as the emotional challenges. They feel vulnerable. Appreciation of temporal pressures augment their anxieties due to the brevity of time left with their partner, in addition to the time consuming nature of being a carer.

They attempt to create a stable routine, a 'false normality', to gain respite from coping with all the adaptations and learning. They try to normalise their days within the abnormal situation. As their partners deteriorate further, lay carers reflect on the strengths and limitations of professional carers who are participating in their world. They cope with the continuous interventions from professional carers including physiotherapists, district nurses, speech therapists, dieticians and neurological consultants. Lay carers increasingly realise how no professional can influence their partner's outcome and these limitations magnify with their partner's deterioration.

They sense the approaching end of their journey with their partners. Despite all their learning and coping strategies they are challenged by the final demand. They return to their anxieties of impending loss which had been shadowed by their activities of care. The impending loss is multidimensional; loss of their partners, loss of using their adaptation and learning, loss of their role as carers and partners. It is also about preparing to move to the next stage of their lives.

As the lay carers offered their stories, talking allowed them to think things through. It highlighted their powerlessness over MND and shed light on the reality of their situation. The situation which was almost too unbearable to admit to themselves alone. The ten lay carer categories are all inter-related as illustrated in the model in Figure 9.

Figure 9. Inter-relationship between the LC categories



7.2. DE-STABILISING IMPACT OF IMPENDING DEATH OF SPOUSE

The lay carers (LC) participation towards the medical diagnosis varied. It depended on whether the cared for informed their partners of their concerns or whether the cared for tried to protect them from the awful reality. Although the LC's may have been aware of some difficulties being experienced by their spouse, its importance was not always acknowledged; 'she used to trip over the kerb, trip over paving slabs and it was a bit of a laugh really because we'd say, 'Mavis could trip over a match stick' ..I never took much notice about all this but she did' (LC2). However, once the diagnosis was confirmed, the realisation of an uncertain future de-stabilised their lives.

LC1 Dread
LC3 Angst of terminal disease
LC4 Heightened uncertainty of life
LC5 Shattered
LC6 Uncertainties of life

The individual categories illustrate the de-stabilising effects of the diagnosis. Fear was a predominate emotion coupled with a sense of dread of the future; 'It's a dreadful situation for me.. quite frightening' (LC1). This initial fear has resonance with their partner's 'existential shock' which combines into the exclamation of, 'I hate it. I hate it. It takes away your future, It's kind of gone' (LC3). Her future dreams and expectations are dashed as she realises she has to cope with watching her husband die rather than sharing a life together.

Another lay carer reports being 'Shattered, because it's pulled me down' but acknowledges how it must be faced as '...you mustn't try to hide it and think that it's going to go away because it's not' (LC5). LC6 confirms the feelings of the other lay carers with his response, 'it's horrid.' but adds, 'I'd always thought everything was curable or at least you had a chance' (LC6). He has to learn to cope not only with his life de-stabilised but also his belief in medicine.

7.2.1 Implications of category 'De-stabilising impact of impending death of spouse'

The lay carers realise their partners face an inevitable slow death. The effects of the disease process will have unprecedented effects on their own lives in terms of effort and skills they need to learn. Their future plans cannot be realised as only uncertainty lies ahead.

Practical implications

A: Lay Carers

- realisation that their partners are dying
- they will face their future alone
- they are seen as the natural carers for their partner until death
- their previous life-plans, dreams, assumptions and expectations are lost

B: Cared For

- questions may arise including 'Is their partner capable of caring for them to the end?'
- what will happen if their partner is not up to caring for them?

- will their partner still love them if they deteriorate so badly and cannot communicate?
- what will happen to their partner after their own death?

C: Professional Carers

- need to be aware of the shock that lay carers are experiencing
- appreciate the de-stabilisation on the lay carers lives
- need to be supportive to the LC's to help them cope

Philosophical implications

A: Lay Carers

- a new way of being needs to emerge - questioning how they are going to cope? How will they handle their new role as carer?
- facing the death of one's partner highlights their own mortality

B: Cared For

- the cared for have to find new way of being with their partners which may have relationship inferences
- their own death means leaving their partners behind

C: Professional Carers

- need sensitivity towards their clients who are entering a field of change, stress and vulnerability
- need to engage and offer emotional support to the MND families
- need to appreciate they are dealing with traumatic life events and impending death.

7.3. SEARCHING FOR ANSWERS

Lay carers begin questioning the situation and to search for answers as to why?, what?, how? and when? They try to appreciate what the future experience will hold and to ascertain what help might be available.

LC1 Searching for answers
LC2 Knowledge fuels fear of MND
LC3 Negotiating a rationale for the situation
LC4 Importance of information
LC5 Value of MNDA's experiential knowledge
LC6 Answers from MNDA

One lay carer tried reflecting on possible causes of the disease,

' I try to find the reason for it. There is no reason why it happened. He does a lot of gardening and you have chemicals that you use or anything like this could have perhaps [been the reason] or reacting. I just can't understand why' (LC1).

The lack of a clear cause for MND frustrated their search for answers. Available information was focused on the physiological aspects and avidly read by all but LC2. In his case and in contrast to the other lay carers, LC2 held the opinion that knowledge fuels fear. Once he knew the essentials, he steered away from seeking further knowledge, 'We knew what MND was and I knew there was no cure and that was that.......I try to push it to one side, if we don't talk about it we're alright' (LC2). This reaction has echoes of denial and isolation (Kubler-Ross 1969), familiar in death and dying stages.

One couple arrived at the diagnosis themselves 'we've got this medical book and we obviously looked things up about nerves because it was a nervous disorder and [MND] seemed to fit the picture' (LC3). After the diagnosis was confirmed their thirst for information was unquenchable, 'I think we've got about three or four piles of books on the subject now' (LC3). However, when this couple realised his death was approaching, knowing about the disease and having all the literature around became senseless to them. Knowing about MND still rendered them powerless so 'I've given the books away to various people' (LC3). They stopped searching for information and focused on being there for each other.

The need for knowledge was to develop a sense of meaning and understanding about the disease. Lack of knowledge augmented uncertainty and presented a feeling of being out of control. Accurate information from professionals was assumed. MND4's prognosis was initially stated as 'between 3 and 30 years' so she and her partner acted on the optimistic view and started a family. However, soon after the birth her condition deteriorated quickly.

They were then given revised information 'Well of course you know the average [MND life-span] is three years' (LC4). This information devastated them as it was new knowledge. Again they had to readjust dreams and plans according to the more acute significance MND would make to their lives. Although they gained much joy from their new born son, the importance of accurate knowledge is highlighted here, as this meant the son would be motherless at a very early age and the father left to cope alone.

Lay carers soon realised their powerlessness over MND and so experienced frustration and anguish. They knew they suffered with their partners as 'it's a terrible thing. I think it's so different from any of the other complaints that a person has all their faculties, knows exactly what's happening and cannot do a darn thing about it' (LC5).

Lay carers found the MNDA particularly helpful in searching for answers to what is it going to be like? Members of the MNDA had experienced the total situation from being lay carers themselves to losing a relative/friend. They had the 'lived experience' and subsequent 'knowing' about the processes involved and could relate to the lay carers from this lived-experience perspective. Apart from LC1, who could not bear to consider how the disease would progress and contained her searching for answers to causes of the disease, all the lay carers remarked on the invaluable support and information they gained; 'MNDA is bloody good. It has a publication, there's the story of a farm worker in Cornwall who has MND that I read and it gave me valuable insight, it's written by herself' (LC6).

7.3.1. Implications of category, 'Searching for answers'

Seeking information about MND, its epidemiology, trajectory and problems was a particular need of the lay carers. A need which they normally shared with their partners. Once aware that there was no cure, the search focused on understanding the experience through listening to the stories of others. They began learning from others' experience to help themselves.

Practical implications

A: Lay Carers

- the need for access to written information about MND
- the need for access to the MNDA

- the need for experienced people to be available to listen and respond to their questions
- the need to learn about the experiences of others

B: Cared For

- the cared for need to create meaning out of their situation and this search could be achieved together
- listening to knowledge from people in the MNDA was a source of great comfort and security

C: Professional Carers

- need to recognise the importance of clients receiving information
- need to have accurate, reliable information available about MND and be able to answer questions with honesty
- need to be able to judge the timing, need and level of information required by lay carers through developing knowledge of the lay carers
- need for appreciation of the value of MNDA for clients and selves
- need to realise the central role lay carers have in influencing the needs of the cared for

Philosophical implications

A: Lay Carer

- searching for meaning is a complex endeavour and takes time
- a new way of being is forced on the lay carers. Answers to practical questions are available from texts but answers to emotional and experiential questions of what will it be like could only be found from others who had been through the experience.
- linking with another lay carer through MNDA literature was a reported supportive strategy
- searching for understanding of a new way of being may be linked to acceptance of their partner's impending death and their potential aloneness
  and their search for a wider meaning

B: Cared For

- seeking answers to make meaning from crisis situations is a human trait and both partners are affected in the potential for new ways of being
- the search for a wider meaning indicates the reflective influence of a life-threatening disease

C: Professional Carer

- need for awareness of reflective influence a life-threatening disease has on the patients and lay carer
- need for awareness of the struggle the partnership endures through creating a new way of being
- need for sensitivity in approach to offering information about MND
- need for co-operation with lay agencies that have different stances in their experiential knowing about MND

7.4. FORCED LIFE CHANGES IN CARING FOR ANOTHER

All six participants experienced 'forced life changes' resulting from their partners' disease. Role changes are central to this category. Lay carers had to abandon their own leisure pursuits, learn new skills, take on new responsibilities and often do the work of two people. Some changes were embraced, others were considered onerous but all were forced through the effects of MND. The contributing individual categories agreed on the loss of personal freedom, realisation of the burden of lay caring and recognition that caring for another with MND was a full time job (see appendix 12 for remainder of supportive evidence).

LC1 Response to forced life changes to lifestyle
LC2 Loss of own life
LC3 Life changes
LC4 Forced restrictions
LC5 Forced personal losses
LC6 Forced changes on carer

7.4.1. Implications of category 'Forced life changes in caring for another'

A change of circumstances in one partner creates a change in the other. The extent of that change is almost a correlation; as the person with MND deteriorates, the responsibilities of their partner increases.

There were some outcomes in terms of learning new skills and developing personal confidence but more frequently the experience was of never-ending hard work, resulting in exhaustion.

Practical implications

A: Lay Carers

- an increase in responsibilities meant that there was less time for themselves
- caring is viewed as a full time job, worse at night.
- outside practical help was required, particularly at night, but reluctantly sought
- additional roles and responsibilities may stretch the resources of a lay carer beyond their physical and emotional capabilities

B: Cared For

- awareness of the exertions and pressures on their lay carers may encourage them to be receptive to external help/respite interventions
- although the cared for do not wish to relinquish all roles and responsibilities, negotiation with their lay carers may help identify which roles and responsibilities they could maintain to help themselves and relieve their lay carers
- guilt may develop in the cared for as they see the extra effort their partners are having to invest

C: Professional Carers

- awareness of the pivotal role of lay carers is vital and the stresses they endure in terms of physical, emotional and role change
- involvement of lay carers in decision-making is imperative, as without them the cared for may not be able to remain at home

- economic implications of hospitalisation are vast, so it is more cost effective to support a lay carer to continue in the home
- suggestions of respite care may be more welcomed if encouraged by a professional carer

Philosophical implications

A: Lay Carers

- their whole being is under stress; no time for themselves can lead to emotional and physical exhaustion. Their own needs may become subsumed and resentment develop
- reduction or removal of their hobbies and interests gives them a sense of loss of themselves as well as an anticipatory loss of their partner
- a change in the sense of self through a forced situation can result in internal tension
- the importance of voice: seeing their partners as non-communicators resulted in not seeing the person they knew

B: Cared for

- the basis of the original relationship affected their listening skills for each other
- appreciation of the effects of change might help them accommodate and develop new ways of being together

C: Professional Carers

- sensitivity to lay carers is necessary
- encouragement and emotional support is needed for lay carers
- listening to lay carers' emotional stance would offer insight into their coping progress
- predicting emotional/physical exhaustion early and arranging respite might help prevent a crisis of being for lay carers

7.5. LEARNING THROUGH CARING

'I think caring is underestimated' (LC5) highlights a significant learning outcome based on the lay carers' accrued experiential knowledge. Lay carers had to learn both practical and emotional aspects of care which they all found challenging, 'I know what it's like now to have to care for someone. I just feel sorry for everybody who has to do it' (LC2). Learning to care involved learning problem solving skills, practical skills, harnessing personal and professional resources to care and developing skills of empathy.

Not all lay carers were successful students, as although, 'Some can cope with it very well. I thought I could but I don't think so' (LC1).

LC1 No personal resources to care
LC2 Learning through doing
LC3 Using personal resources to care
LC4 Learning to care from professionals
LC5 Learning to think like the cared for
LC6 Learning care strategies

7.5.1. Implications of category 'Learning to care'

Caring for one's partner is motivated by love but requires learning new skills and ways of being. It is demanding, exhausting and requires not only physical resources but much investment of the emotional self. Learning empathy and selflessness was required in caring for a partner. Although professional carers offer practical help and guidance, problems were continuous. As their partners' physical deterioration progressed it often demanded further innovation to cope. Positive feedback from any experience re-motivated the lay carers.

Practical implications

A: Lay Carer

- caring is under-estimated
- practical caring for a disabled person demands practical help in many domains such as lifting and handling, nutritional advice
- learning to care is exhausting. Rest and relaxation should be built in to the timetable

- need for problem-solving skills to overcome particular situations related to activities of living
- need for professionals to educate lay carers in practical ways of caring

B: Cared For

- offering positive feedback to the lay carers may motivate them to learn and care more
- appreciating lay carers are learning and cannot solve all encountered problems

C: Professional Carer

- lay carers need to learn practical skills and can be helped to do so by the professionals
- questioning lay carers concerning their coping mechanisms and their needs is imperative to capture these learning needs.

Philosophical implications

A: Lay Carer

- learning to care requires love
- requires motivation, an open mind and the ability to ask for help
- a partner has emotional connotations and requires supportive strategies for adjustment of roles
- previous relationship bonds affect the caring dynamics
- ability to communicate with your partner affects the ways of seeing your partner as a person

B: Cared For

- caring is demanding and uses up many personal resources which may deplete the lay carers' reserves
- communication is vital to remain a person in the lay carer's sense of being

C: Professional Carer

- need for awareness of the relationship bonds between lay carer and the cared to appreciate its potential course
- need to promote ways of communication between lay, cared for and professional to keep the focus on the person rather than the body

7.6. THE VULNERABILITY OF BEING A CARER

The forced life changes and learning to care have their costs. 'Vulnerability' captures the suffering and emotional distress experienced by the lay carers; 'This is horrible. It's worse than cancer' (LC2); 'I hate it. I hate it' (LC3). Social isolation, suffering, caring received from others and caring for selves are four elements of this category.

LC1 Distanced from others/Caring for self
LC2 Caring is hard work/Need for others to help
LC3 Suffering of the lay carer/Need for support in caring
LC4 Emotional vulnerability/Need for support in caring
LC5 Emotional caution/stress/Suffering demands care for the carer
LC6 Importance of hope and goals

7.6.1. Implications of category, 'Vulnerability of being a carer'

The hard work, emotional and physical involvement soon led the lay carers to realise they were suffering as well as their partners. They experienced social isolation and vulnerability but managed to find support from friends, family, professional and voluntary carers and not least the cared for themselves.

Practical implications

A: Lay Carers

- caring is hard work, physically and emotionally demanding
- social isolation is heightened as their partner's communication ability declines
- physical and emotional suffering is experienced
- lay carers need help in terms of physical assistance combined with moral support
- MNDA members can offer experiential knowledge for lay carers

- co-ordination of professional carers was a supportive strategy for lay carers

B: Cared For

- realisation that caring is demanding of their partner may help them be supportive in return
- the need to accept care from others is important to be supportive to their partner
- the need to remain understood is crucial in maintaining relationships with people

C: Professional Carers

- awareness of potential suffering lay carers endure is vital so they can look for signs of distress and present alternative strategies
- particular attention should be offered to lay carers in terms of their own health and safety in being a carer
- maintaining communication channels between the cared for and others is vital for success
- lay carers are pivotal and should be nurtured
- the need for regular attendance on clients is clear to reduce their social isolation

Philosophical implications

A: Lay Carers

- social isolation is a precursor to suffering as it promotes a sense of abandonment and being alone in the face of adversity
- receiving care from others needs to be accepted and actively pursued to balance their emotional stress
- strategies to care for self require a sense of self-importance which can be diminished when caring for another

B: Cared For

- caring for their lay carer is well received but needs promotion to redress the balance of the relationship

- appreciation that lay carers are suffering as well as the cared for stimulates the need for external support

C: Professional Carers

- professionals need to engage with lay carers to appreciate their vulnerability
- awareness of the social isolation and personal suffering of the lay carers may encourage greater understanding of the effects of their caring and promote professional support
- professionals need support in caring and appreciate the limits of their involvement capacities; inter-professional co-operation is one positive approach for this

7.7. TEMPORAL REALISATIONS

The concept of time is bought sharply into focus for the lay carers. Two dimensions emerge; first the limited amount of time they have left with their spouse and second how the speed of the disease highlights the immediacy of need, in relation to receiving equipment and help.

LC1 Timing of help
LC3 Temporal shifts
LC4 Temporal pressure
LC5 Temporal concerns
LC6 Centrality of time

7.7.1. Implications of category 'Temporal realisations'

Time became a central focus as lay carers knew it was limited for their continuing partnership but also was central to managing care, help and equipment. The limitations of professional time was experienced.

Practical Implications

A: Lay Carers

- time is precious and needs to be spent wisely
- it is not possible to look too far ahead but a balance needs to be gained with planning

- lack of organisation of professional carers creates more problems
- equipment needs should be continually assessed to get the timing right

B: Cared For

- time is precious and needs to be spent wisely
- it is not possible to look too far ahead but a balance needs to be gained with planning
- if equipment can be organised appropriately it increases the chance of a greater quality of life
- lack of organisation of professional carers is not conducive to temporal planning

C: Professional Carers

- the need for equipment stores and professional access is made clear
- the need for regular accurate assessment of client need is clear
- there is a need for a professional carer to co-ordinating services through a team approach .
- regular attendance at a home situation is vital

Philosophical implications

A: Lay Carers

- time is the essence of life and needs to be used wisely
- time cannot be bargained with, it runs its own course
- the finite nature of time is sharply realised in this context

B: Cared For

- the shortness and importance of time is shared between partners

C: Professional Carers

- need for sensitively and awareness of the time pressures on lay carers
- need for appreciation that lay carers experience time in two dimensions; time left with their partner and the timing of help

7.8. THE FALSE NORMALITY

Lay carers had had their sense of routine removed but tried to establish new routines as the situation demanded, 'Having a routine keeps things ticking for me' (LC2). This new routine however usually revolved around the needs of the cared for as, 'my life revolves around Henry's life now' (LC3) which was her new normality. A sense of stability permits 'normal' life to continue, although lay carers knew that their attempts for a new normality actually created a false normality

LC2 Normality before reality
LC3 Re-creating normality
LC4 Striving to maintain normality
LC6 Denial of reality

7.8.1. Implications of category 'The False Normality'

One way of coping with a distressing situation was to create a sense of the normal within the abnormal. Although this could not avoid practical issues it did offer a strategy for not confronting their situation to allow relief from the acuteness of the tensions and pressures.

Practical implications

A: Lay Carers

- creating normality when it does not exist allowed the lay carers to cope with day to day practical issues

B: Cared For

- the cared for also strove for a sense of the normal, being compatible with the lay carers

C: Professional Carers

- professionals need to be aware of the need for a level of normality even in extreme situation.
- planning visits would facilitate 'fitting in' with the routines established by the families

Philosophical implications

A: Lay Carers

- a sense of normality, although false, offers a sense of coping
- normality allows a person to adapt to extreme situations
- normality allows emotional angst to be rested

B: Cared For

- a sense of normality, although false, offers a sense of coping
- normality allows a person to adapt to extreme situations
- normality allows emotional angst to be rested

C: Professional Carers

- professionals need to be aware and supportive of the need for a sense of normality

7.9. STRENGTHS AND LIMITATIONS OF PROFESSIONALS

All six lay carers experienced strengths and limitations of care professionals. The three main areas are, Strengths in functional skills, Limitations in inter-professional co-operation, Need for more emotional care.

LC1 Strengths and limitations of professionals
LC2 Strengths and limitations of professionals
LC3 Support from professionals
LC4 Supportive professional interventions
LC5 Need professionals
LC6 Caring needs teamwork

7.9.2. Implications of category 'Strengths and limitations of professionals'

Lay carers needed and gained support from professionals but they also highlighted significant areas of deficits.

Practical implications

A: Lay Carers

- professional practical interventions and the supply of equipment for people with MND improved the lives of the lay carer
- lay carers appreciated professionals volunteering helpful solutions to difficulties and reassuring them
- a co-ordinated approach through a team mechanism was greatly valued

B: Cared For

- the support and limitations of professionals affects the lay carers

C: Professional Carers

- team work with a co-ordinator is supportive action for the lay carer
- prompt supply of equipment is seen as a strength
- need for accurate assessment, using listening skills and questioning about mobility and hygiene needs should be addresses to both cared for and carer
- time spent should be clear and unhurried, appointments made should be regular and kept even when functional interventions are reduced

Philosophical implications

A: Lay Carers

- lay carers need to experience from others a sense of genuine involvement in the tragedy
- empathy from professionals is received as caring
- Being is as important as knowing, if not more so
- a cheerful disposition was considered a positive attribute

B: Cared For

- clients need to experience from others a sense of genuine involvement in their tragedy
- empathy from professionals is received as caring

- Being is as important as knowing, if not more so
- a cheerful disposition was considered a positive attribute

C: Professional Carers

- Being is as important as knowing, if not more so
- offering a sense of genuine concern and involvement is received as caring
- visiting when there is no function interventions offers the message of emotional care

7.10. PREPARING FOR LOSS

Thinking about life after your partners death is a most private emotion. This made it a very sensitive area of enquiry. However, there was evidence that towards the end of their partner's lives, lay carers began preparations for their impending loss.

LC1 Preparing for loss
LC3 Preparing to move on
LC4 Life after loss
LC5 Plans in hand
LC6 Look beyond her death

7.10.1. Implications of category 'Preparing for loss'

Once the lay carers had journeyed through their shock, searched for answers, coped with life changes, learnt how to care and manage their vulnerabilities, they realised that they also had to prepare for the actual death of their partner. This meant thinking beyond the death and to their own lives. Much time and energy had been devoted to the person with MND, it was quite hard for the lay carer to consider themselves again.

Practical implications

A: Lay Carers

- economic concerns meant jobs had to be sustained throughout the periods of illness, it was recognised this would give them a focus after their partner's death

- no compassionate leave appeared to have been offered to lay carers with the promise of returning to their jobs after the death of their partner
- the need for a ‘post-death event’ seemed high on the agenda for the lay carers once their partner had died.
- talking with their partners about their own future appears a difficult topic

B: Cared For

- avoidance of the subject of their partner’s future may have caused further isolation

C: Professional Carer

- being sensitive to the possibility of opening up a conversation in this domain may be useful

Philosophical implications

A: Lay Carers

- thinking of your life after your partners death was a stressful process
- it was so sensitive they found there was an absence of anyone to talk this through. There were notions of guilt talking it through with me. This whole area of care for the carers appeared neglected. It may be appropriate to refer some lay carers to a bereavement counsellor, even before the event, to offer support in this area.
- the need to be different again came across from the lay carers in terms of their travel ideas and escaping from the situation that had so entrapped them. They would have to create a new way of being
- being together with their spouse in the knowledge that they were to be physically parted was not an easy endeavour - only one couple really managed this

B: Cared For

- recognition that your partner’s life is to continue after your own is a difficult reality. If there is open discussion between partners about the disease and its implications, this might open the way to talk about the surviving partner. This could be seen as a caring act, to talk about the surviving partner and agree some future actions the survivor can take, almost caring beyond the grave. Adoption of this way of being is acknowledged as a challenging route to take

C: Professional Carers

- sensitivity required on the immediate loss of a partner as it leaves a bereavement situation, a lonely way of being, particularly when so much energy has been expended in the 'lost' life
- appreciation of the partner being 'left behind' highlights the need for follow-up care with the option for some discussion before the death of their partner

7.11. REFLECTION HIGHLIGHTS REALITY

In parallel with the cared for, when asked how the guided conversation had influenced the lay carers, they acknowledged how talking about their experiences had highlighted their reality.

LC1 Reflection highlights powerlessness over MND
LC3 Think things through in refection
LC4 Revelations gained from refection
LC5 Reflection focuses reality
LC6 Reflection challenges thoughts

7.11.1. Implications of category, 'Reflection highlights reality'

Reflecting on their stories and experiences with a stranger made them consider the reality of their situations. Two lay carers did not appreciate this process although the other four recognised some value with one locating a lack of emotional provision in his caring role. The guided conversations were not developed to be a therapeutic tool but suggest that talking to a stranger can be a positive support strategy.

Practical implications

A: Lay Carers

- reflecting through speech about one's situation makes it real

- talking in the majority of cases was seen as a positive experience as it clarifies their position
- leaving the thoughts with a stranger resulted in less anxiety as to how such distressing experiences could affect them

Philosophical implications

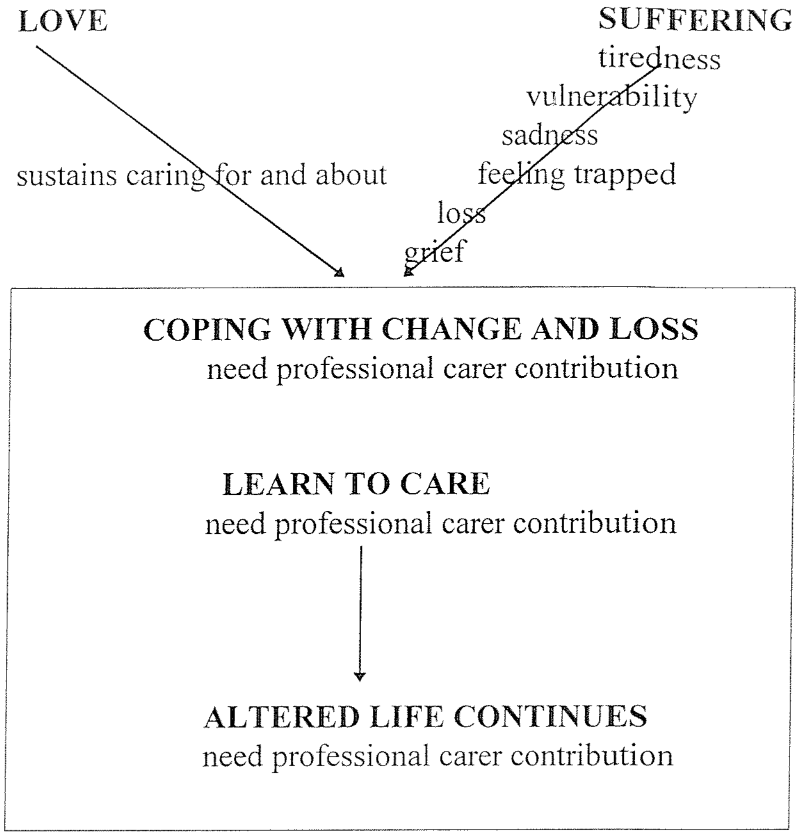
A: Lay Carers

- different ways of being demand different approaches
- for some people, realisation of their strengths and weaknesses in caring can be verified for them and help them identify gaps in their ways of caring
- reflection offers a sense of taking stock of their situation and appreciation of their ways of caring

7.12. LAY CARER VALUE OF CARE MODEL

The central value to sustain lay carers seems to be the love they have for their partner but this love is closely associated with their own suffering. Practising their love through caring in extreme situations means they suffer a great deal. They try to remain strong, motivated and sustained by their love to cope with the changes they have to make to their own lives. They have to learn many aspects of care in the face of shock as the disease progressively reduces their partner's physical and communicative abilities to the final stage of death. The lay carer model of caring in figure 10 diagramatically represents these caring values whereby the lay carer is ultimately tested with establishing an altered way of being through an altered life.

Figure 10. Lay carer value of care model



Caring is hard work, a full time job and forces life changes of great magnitude to the extent that one's former life is lost. The caring offered can be linked to the concept of personal growth for many. But if personal resources are inadequate or the love between the partners is insufficient then the suffering overthrows the love. The lay carer does not cope with change, rather they resist change which makes it more difficult to learn how to care, to cope with the shock of the disease and almost welcome the inevitable death of their partner to reduce both of their suffering.

The professional care potential to make a contribution lies in the areas of reducing the lay carers' suffering. This can be achieved in four areas, identified as being valued by the lay carer; acknowledging the suffering they endure, supporting the lay carer with the challenge of change, learning how to care and offering emotional support throughout.

This contribution could aim for the ultimate outcome of supporting the lay carer through their altered life, even after the death of their partner. If a lay carer was not sufficiently motivated and sustained by love to care for their partner throughout the disease, the professional carer supporting the lay carer could act as a sustainer. This model highlights the need to follow the care needs of the lay carer as much as the care needs of the patient.

7.13. SUMMARY OF CHAPTER

This chapter has presented the group category findings as constructed from the evidence of the lay carers. A temporal model of the experience of caring for a partner with MND has been presented together with a lay carer value of care model. This latter model highlights the value of love and the capacity to suffer. Coping with change and loss is actualised by learning to care with love as the motivator for success. The role of the professionals is exposed as not being able to focus sufficiently on the lay carers. This deficit suggests the need for all professionals to be aware and action this process or for a designated professional to care for the partner of a dying disabled person.

CHAPTER 8: THE PROFESSIONAL CARER GROUP FINDINGS

8.1. INTRODUCTION

This chapter presents the findings from the professional carer participants. As they were identified by MND/LC3 as offering 'good practice', their findings need to be seen in this light. Their evidence contributes to developing our understanding of professional caring values to which people with MND and their lay carers are exposed. This evidence allows the third angle of the 'caring triangle' to be plotted. Eight categories are constructed from this group and are presented in temporal order (table 17).

Table 17. Eight categories from PC participants in a temporal priority order

1. *Strengths of professional role*
2. Ideals of care
3. Role limitations
4. Situated friendship
5. Learning potential in professionals
6. Critical nature of time
7. Importance of inter-professional co-operation
8. Continuum of reflective thinking

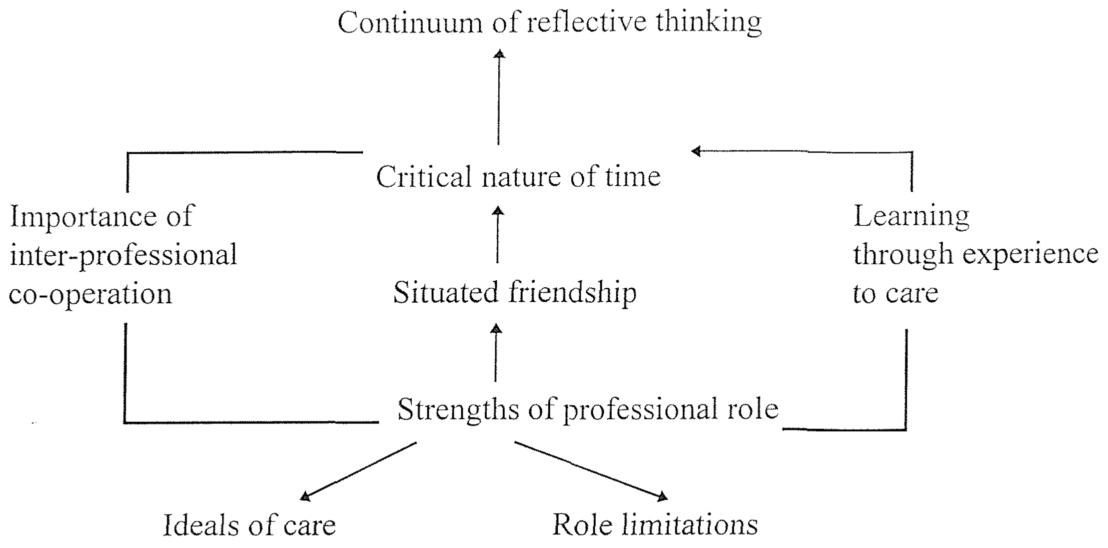
Commonalties of caring values outweighed any differences. They all exhibited functional roles which served different aspects of the human body, except the district nurse. Though the collective intention is to care for the patient, not one professional cares for the total being of the person who is diseased. Whilst the cared for is struggling to remain a human being despite MND, and the lay carer is suffering whilst coping with change, it seems discordant that the majority of professionals are primarily focused on the patient's declining physical functions. It is not surprising therefore that there is less alignment in the findings from the professional carers to the preceding two groups.

Using a theatrical metaphor, if one accepts the people with MND are the leading players and the lay carers the main supporting actors, the professional carers are the cameo roles. The professional carers (PC's) do not have the same level of involvement, invested time, emotional inter-play, physical hands-on or potential loss compared to the cared for and the lay carers. The cared for will be losing their lives, the lay carers losing their partner and future dreams. The professional carers will lose a patient but ironically the fact that someone is a patient has given them a professional role. However, it could be argued that professional carers adopt the leading role, allocate the person with MND the supporting acting role and locate the lay carer in the cameo role. Different permutations of this metaphor may well depend on the role and stance one holds. In this study the leading actor is considered to be the patient.

The professional stance of assuming the role of leading actors is illustrated through the temporal order of their evidence. They all began their stories recounting the positive functional aspects of their role. Listening and hearing patients stories did not feature. Only after they had exhausted their functional contribution did they explain their ideals and aspirations. These did include ways of being with patients and lay carers. These first two professional categories are in direct contrast to those of the cared for and lay carers, who identify being in situations of extreme threat, shock and making sense of their situation. Indeed the professionals are not under personal threat or duress, so they engage in the caring triangle from their own professional world-view; of professional certainty and role clarity.

The inter-relationship between the PC categories is illustrated in figure 11. Role limitations tend to largely focus on external constraints, such as resource tensions in personnel capacity and economic options for equipment and respite care and a work overload resulting in lack of time for patient care. Functionally they are strong but holistically limited. When their functional remit diminishes, their visits cease, this limits opportunity for the professional-patient relationship. In this functional vein, coupled with the lack of a distinct care professional to focus on the changing nature of being human through illness means this element of care remains unsatisfied. Emotional care becomes a particularly neglected area of care delivery. This gap is despite the intentions and effort of some professionals who struggle to offer a holistic care approach to their practice.

Figure 11. Inter-relationship between the PC Categories



Their personal commitment to care is clear with relational ambitions of friendship and promoting autonomy. Origins of this value base are not attributed to ethical training but their own motivation and learning through experiences. Each category is considered in its own right. Supportive evidence is presented and implications made from each category. Whilst remaining cognisance of the inter-connectedness between the categories, only two are presented with their full evidence. The remaining six are illustrated with the implications. The full evidence is presented in appendix 13.

8.2. STRENGTHS OF PROFESSIONAL ROLE

Strengths of the professional role can be illustrated through five dimensions: functional intentions; emotional support (holistic approach), knowledge coupled with experience, making professional judgements and inclusive approach to lay carers.

PC1 Knowledge, experience, judgements
PC2 Assessment of services to needs
PC3 There for him
PC4 Functionalist nutritional approach
PC5 Power to determine needs
PC6 Authority for action and to reassure
PC7 Functional and emotional
PC8 Finding, telling and judging
PC9 Assessment for independence and adaptation

Functional intentions

All nine professionals discussed functional strengths of their role. The importance of functional interventions has been identified by the clients as they need assistance with mobility and equipment, help with speech and language, and nutritional support. However, two professionals considered their functional care as being exclusive to the detriment of considering emotional needs. These two 'primary functional' professionals explained their roles as promoting nutritional support (dietician) and exercising an authority role (general practitioner). The latter through sanctioning a range of supportive measures, services and equipment offered by other care professionals. The seven 'holist' professionals viewed the patient as a person in a particular context who needs their functional skills but within a relationship.

Extracts from the two 'primary functionalist' professional texts are as follows; starting with the dietician,

'I gave him dietary advice on high protein, high energy intake ... to ensure that he was meeting his nutritional requirements which I've calculated on his current body weight..' (PC4)

and from the general practitioner who saw her role as, 'there to catch any problems they had early, like a chest infection' and in terms of attending the case conference '.... I think a lot of people are reassured by it, by a GP being there as someone to agree or to have some form of authority in a way of what's going on' (PC6).

These two examples illustrate their functional approach. A commonality is that they had minimal physical interaction with the clients and the time spent with MND3 was less than the other professional carers. The GP illustrates, 'I haven't had a huge amount of involvement. I think the district nurse and the physiotherapist and all the others in the team have probably had more really' (PC6). It can be argued therefore that three features may have a significance in terms of the approach taken to caring for someone from a professional perspective; amount of time spent with a patient, proximity of hands-on involvement and the category of needs that the professional can respond to.

The dietician and GP both appeared to spend little time, have no real physical intervention and either had such a specific or general remit that they did not have an opportunity for further intimacy of care.

Emotional support (holistic),

The other seven professional carers offered more holistic approaches. They presented a sense of genuine involvement through wanting to 'know' the patients and carers and acknowledging the importance of continuity of carers. The 'holist' professionals discussed their functional interventions in tandem with their attitude of concern and focus on the person.

The speech and language therapist tells of having 'a deep knowledge about the types of difficulties they are likely to experience' (PC1) but also how being 'a counsellor is very important, to be a listener….I tend to be there to soak it all up 'cos sometimes they need to off-load and you've actually got to take on their burden of grief' (PC1).

In terms of revealing the diagnosis, the participant neurologist offered a best practice picture in terms of how he realises, 'your approach varies with individuals, you tend to have a feel at the end of the consultation how anxious the patients are about their problems'. This informs him to tell the diagnosis only when there is another family member present and to immediately, 'give them some support, declare the diagnoses, get the physio in urgently to see them and probably have some back up at home' (PC8).

Apart from the consultant, the physiotherapist was the most experienced practitioner. She was well aware of the impact MND has on people's lives, in all its dimensions. She states, 'that although you can't stop it happening, you can't stop it getting worse, you can do an awful lot to make it better while it's happening and the changes that have occurred by altering one slight thing and that situation has improved matters for the family' (PC7), such as demonstrating an alternative type of lift or obtaining equipment.

Working closely with the physiotherapist was the district nurse. She clarified her more holistic role as she does 'all the running around, I'm checking his pressure areas, arms and things. I'm there for him really. I get him food (parental nutritional packs), I'm there to talk to them if they want me, setting up the emergency pack.. making sure that he's got everything that he needs' (PC4).

The Nurse Specialist, Disability, and the Social Worker had almost parallel roles in the context of MND3, although the former was concerned with organising health services and the latter the social services. As MND3 had more perceived health needs than social needs the nurse took the lead in his care management.

Although the two roles were alike in many respects, they had clear differences. These can be accounted for in the different economic implications of their services (health care is 'free' and social care is not). In the nurse's approach she negotiated needs with the patient, her stance of intervention was based on how it 'really does depend on the individual, how much they are willing to accept' (PC2). The social worker however, considers her authority first, as it allows her to act as a gatekeeper to services that a patient may require. In her practice she explains she puts the patient's needs first but recognises , 'people's perceptions of social people in authority can be very different than how we perceive ourselves. If we are going in to a house as a social worker we go in with a certain amount of power……. We can move towards equality of a relationship by the sharing of power and how you do that depends on that person and where they are' (PC5). Although this social worker appears to share her power, there is inference that this is atypical for all social work practitioners.

Though the participant care professionals were identified as offering 'good practice', two ways of being can be identified (functional and holistic). It raises awareness of potential differences in value bases between the recipients and givers of care. If we consider the MND/LC reports of the poor attitudes of specific consultants (see MND existential angst and LC strengths and limitations categories), it is disappointing to realise that a functionalist reductionist approach remains amongst care professionals.

Knowledge coupled with experience

The level of knowledge and experience varied between the professional carers in relation to MND. All but the dietician had at least 10 years in their profession (the dietician had been qualified 3 years) but six professionals were facing their first case of MND (see chapter 4 for more details of professional profiles).

The first knowledge gap the majority encountered therefore was 'What do I know about MND?' The inexperienced admitted to reading about MND, from MNDA sources and textbooks in their own discipline. The district nurse stated, 'I suddenly had him on my books which was a bit daunting, we don't know that much about motor neurone disease, it's a difficult one, so many things that could go wrong, I'm just thinking 'help!' I read as much as I could and wrote to the MNDA' (PC3).The GP was also uncertain about MND and 'I had to admit to him my lack of knowledge and how I'm sort of learning as he was' (PC6). However, functional skills were transferable to MND patients as the physiotherapist suggests , 'the problems that we deal with are [the same] for lots of people, mobility problems'. This meant it was the psycho-social approach that was challenging as 'the actual problems are things we are quite used to with other people, it's more the psychological, social problems that perhaps makes MND unique' (PC7).

Making professional judgements

Making judgements is part of a professional's role. In terms of information giving the speech and language therapist suggests,

'you have to weight up whether you feel that the person really wants the bare naked truth or whether they need it delivered bit by bit and whether they are really somebody who actually needs to have something to hold on to and hope for and can only keep going if they've got something to hold on to, that is very difficult' (PC1).

A similar problem faced the consultant. He had to consider his approach to telling the diagnosis and also whether prescribing the drug Riluzole would have any benefits. In terms of the diagnosis, the consultant tried to deliver the diagnosis in hospital when relatives were present. Once he had told a patient on his own which made the family 'very, very angry'; he learnt from the experience, 'to have someone else because they can relate to it better and then they could ask [questions] and [the patient] has the support and they are still in hospital' (PC8).

In terms of prescribing Riluzole, 'it's very difficult for me to judge whether 2 or 3 months longer for a patient is worthwhile... the reaction is quite mixed.. some patients just like psychologically being on something that delays progression.. I think there is a lot of placebo but at least it's a placebo based on a clinical trail… it's really more of a patient's decision than mine' (PC8).

The OT had to judge the timing of introducing and removing equipment. Both served to mark the passage of further deterioration as 'it emphasised the fact that he was getting worse'. To support herself in making these judgements she adopted the strategy of leaving a decision 'up to them really but I would say, 'Is there anything you would like me to take away or shall we re-arrange to get that taken?' (PC9). However, lack of knowledge and experience with MND affected judgements as explained by the GP, 'he wanted my opinion on it [taking the drug Riluzole] and I couldn't give him that 'cos I hadn't had any experience of it' (PC6).

Positive approach to lay carers

Professionals generally regarded lay carers as vital players in care delivery, 'it's all down to the carer, all down to the family and they're having to do so much…..it's the carer that does most of the work' (PC7) . Indeed the district nurse admits to being there for both of them but stated, 'I suppose I tended to concentrate more on his wife because I think she's doing a brilliant job looking after him but underneath she's a very tired lady' (PC3).

The Nurse Specialist, Disability was the team co-ordinator and she would 'make sure that the carer's aware that they have entitlements to an assessment in their own right' (PC2) and the occupational therapist put both patient and lay carer as equal clients on her first assessment visit as she made 'a full assessment of what their needs are, of the user and carer' (PC9) ….I was very aware during that early meeting, of his wife's need to be the main carer and to continue to do that for as long as possible' (PC9). This approach was imperative to sustain home caring. The social worker also promotes the importance of the lay carer as, 'obviously the carer is the focus within that relationship ...if the carer goes down, the whole thing generally collapses' (PC5).

8.2.1. Implications of category ' Strengths of professional role'

This category offers evidence of functionalist and holist-orientated practitioners. They all agree on the importance and appropriateness of their functional interventions and view these interventions as strengths in care delivery. Not all consider the significance of knowing the emotional needs of the patients as part of their concern. They all expressed support for the pivotal role of the lay carer.

Practical implications

A: Professional Carers

- professional functional roles are required by people with MND
- functional roles offer patients a level of knowledge and expertise to draw on to meet their needs
- fulfilling a functional role alone is not considered sufficient by the majority of professional carers
- functional knowledge and experience support a professional's expertise
- making professional judgements involves sensitivity to patient's needs and situation as well as the functional context

B: Cared For

- professional functional roles are needed as fulfilled by the professionals
- care from an experienced professional is more likely to be holistic as opposed to only functional and therefore more desirable
- experienced professionals make sensitive judgements, putting the patient's situation first which is desirable

C: Lay Carers

- professional carers are sensitive to the important role of lay carers which is self-motivating
- functional roles assist lay carers as well as patients

Philosophical implications

A: Professional Carers

- professional carers may hold different value bases (functionalist/holist) amongst themselves
- these values can be linked to their level of experience and contact with patients (amount of time spent with a patient, proximity of hands-on involvement and the category of needs that the professional can respond to).
- knowledge coupled with experience assists in making sensitive professional judgements

B: Cared For

- there may be a diversity of caring values encounted amongst professional carers which will affect care receipt
- professional power may be detrimental to patients if professionals do not put the patient first in decision-making
- there is no guarantee that emotional empathy or human support will be offered which could leave patients with a gap in their care needs

C: Lay Carers

- although professional functional roles should be fulfilled, emotional support may or may not be offered
- consultation with and being valued by professionals is a supportive strategy for lay carers

8.3. IDEALS OF CARE

Professional ideals of care can be grouped into three areas; relating to principled ethical values of promoting autonomy, beneficence, non-maleficenece, justice and honesty; professional ideals of holism; caring ethics of being personally involved as human to human, recognising suffering, being grounded in the patient's world, seeking understanding and social interaction with a patient to reduce suffering.

All professionals alluded to such principles but only four identified caring ethical values; these four professionals had most contact with the cared for.

PC1 Primacy of the patient
PC2 Striving for ideals in care
PC3 Ideals in caring
PC4 Ideals in caring
PC5 Ideals in caring
PC6 Ideals in caring
PC7 Strategies to assist with impact of MND
PC8 Ideals in caring
PC9 Ideals in caring

Principled ethical values

A sense of 'commitment to the best practice' was spoken of by the social worker to 'always give the person their choice' (PC5), thereby upholding the principle of respect for autonomy. This principle was highlighted by the dietician who stated, 'I don't feel that I can dictate to them' (PC4) and taken further by the occupational therapist who encouraged active participation in decisions about useful equipment. She states they, 'were keen to actually look at the equipment themselves and to being pro-active in that so I said, 'Well, go along to the aids and equipment centre and have a look for yourself and see what you think' which they did' (PC9).

Respecting a patient's autonomy, despite disagreeing with their decision is considered important, 'if they've made a decision which you personally wouldn't make, I don't think it's up to you to say, 'No, I'm not going to support that person 'cos I don't personally believe in it' (PC2).

Honesty was illustrated in terms of making promises, 'If you say you're going to do something, I think you've got to follow it through whatever… I think you've got to honour your promises and not make promises you can't keep' (PC2). Honesty was also a challenge when uncomfortable questions were being asked, 'in the initial stages when he wasn't too bad he would ask me things like, 'Will I be awake and not be able to breathe?' and I was able to talk about some of those fears at the beginning when it wasn't a problem…. But you can't say it won't happen' (PC7). The testing of their ideals is the ultimate challenge.

Honesty was tempered with a sense of protection. The consultant sometimes did not tell a patient their diagnosis at the beginning, 'I think you have to give a little protection and give them at least [something] to look forward to what's left of their life ...you can't really lie and give them false impressions that it's[MND] not going to progress so you say, 'Well, it may progress, your type of motor neurone disease... there are many variants of MND that take much longer, so that's on the good side for you' (PC8).

Professional holism

Holism was talked about in an ideal sense, 'I'm just conscious that you need to look at the whole person and not just the physical side of things'(PC3). Part of this approach identifies the need for 'continuity as well as consistency of approach which I know is perhaps an ideal but if you don't have your ideals where do you start' (PC3).

The social worker also talked of the holistic ideal as she suggests the 'The holistic approach to an assessment takes in everything and tries to look at everything that's going on' (PC5). This is supported by the specialist nurse, disability, who adds one does 'not just see the illness but see the whole background.... I think if you can help the whole family come to terms with whatever's going on then they can all help each other better' (PC3).

Caring ethics

The speech and language therapist was acutely aware of the problems communication difficulties can raise as it 'makes them invisible people' (PC1). Within this lens she sees part of her role to 'share their burden of grief'. She lets them know she has some understanding of their feelings and frustrations and wishes to be with them in their distress. She describes that 'if you are in a difficult place and you're there on your own it's much more alarming than if you've got somebody there with you... somebody there's who's experiencing it or sharing a part of it' (PC1). This sense of sharing a burden meant giving something of yourself to the patient through attentive listening, presence and sharing their distress.

Sensitivity to clients' needs was illustrated through awareness of the struggles that clients and carers endured and how the course of their coping strategies varies which demands being, 'sensitive to what you are saying and not trying to get too far ahead of people really.

It takes them time to move down the road to reach what's happening and what's going to happen' (PC9).

Within a caring ethic, there is need for some professionals to feel they have a relationship with the patient as 'I don't just want to be a figure in a uniform that just comes in and does something and goes away again' (PC3). The district nurse wanted to work with the cared for as a friend and supporter. The professional's statement is a mirror of the patient's situation who equally does not wish to be a nameless patient. This reflects the importance of needing to be considered a person first, whatever role we play.

Attempting to be grounded in the patient's world was an aspiration of one professional carer who stated she tried to be, 'flexible, caring, sorting out the various problems as they crop up, mainly to be in touch with them, be in touch with that person and that family and the other carers' (PC7).

The caring ethic also meant consideration of the lay carer's world. The social worker predicted to visit LC3 after her husbands death as 'I worry what's gong to happen when he dies… it will be a huge void…I'll look in at what's going on' (PC5). This illustrates a level of commitment and involvement beyond the patient focus.

8.3.1. Implications of category 'Ideals of care'

Professionals indicated how their ideals are worth striving for even if they cannot always be attained. This category captures their ideals of valuing people with a moral foundation. It drives their practice even though it may on occasion be clouded by more practical concerns.

Practical implications

A: Professional carers

- ideals are the basis for practical interventions and can be positive when they match with the patient's ideal of care
- ideals do not always match reality due to role restrictions and limitations
- all professionals have ideals which are ethically based even though there may be contextual interpretations

B: Cared For

- if a professional has ideals of care which are rooted in principled ethical structures then these lead the professional to respect the patient's autonomy which leads to respecting the patient as a person which is congruent with the patient's needs.
- if a professional does not have ideals of care rooted in ethics, this could present problems
- an element of protection is offered the patient, from neglect or abuse if professionals have ethical ideals

C: Lay Carer

- an element of protection is offered the lay carer, from neglect or abuse if professionals have ethical ideals

Philosophical implications

A: Professional Carers

- ideals and action can present a dissonance in practice (theory-in-use and theory-in-action) and be a source of frustration for carers
- awareness needs to be raised between what one's ideals are and how one practises
- being considered a human being is an important ideal for some professionals as well as patients
- contextual interpretations of ideals of care could lead to tensions in delivery of patient care if these interpretations are not shared inter-professionally
- three approaches to ideals are identified, principled ethics, holism and caring ethics. The first two categories had more membership than the caring ethics which suggests mutuality and reciprocity aspects of care are not high on the professional agenda

B: Cared For

- ideals that are congruent can only facilitate care receipt but difficulties would emerge if there was dissonance
- a professional's lack of ethical ideals of care would diminish the patient's sense of being human

C: Lay Carers

- ideals of care that are congruent can only facilitate care receipt but difficulties would emerge if there was dissonance

8.4. ROLE LIMITATIONS

Role limitations were perceived as an uncomfortable admission. Two main areas are identified, the functional limitations and the external economics which affect delivery of care. The individual categories contributing to this group identified in the box.

PC1 Limitations of professional role
PC2 Limitations to professional caring
PC3 Limitations to professional caring
PC4 Limitations to care
PC5 Professional constraints to caring
PC6 Limitations of professional role
PC7 Constraints on professional role
PC8 Limitations of professionals
PC9 Weaknesses in service for MND patients

8.4.1. Implications of professional category 'Role limitations'

Role limitations were identified as aspects of care that could not be delivered due to lack of personnel, time, money and equipment. This led to frustrations for the care professionals as they could not attain their ideals of care.

Practical implications

A: Professional Carers

- all the professional carers with continuous patient contact, (PC1,2,3,5, 7,9) felt passionate and disturbed about the lack of economic resources available which acted as a constraint to the care they desired. Letters of complaint to the financial managers had no impact.
- the gap in emotional care for people with MND was considered a reality and needed attention
- the development of a specialist nurse for people with MND who could offer specific counselling and support was perceived as a valued potential development

B: Cared For

- economic limitations on care can mean false promises and raised expectations that cannot be attained through health and social services
- limitations of equipment can lead to unnecessary hardship whilst dying
- lack of professional time is detrimental to care

C: Lay Carers

- lack of practical support through economic restraints makes their lives harder and may force them to stop caring at home. This would have higher financial implications to health and social services
- lack of professional time is detrimental to care

Philosophical implications

A: Professional Carers

- role limitations need to be brought into the consciousness of professional carers and the nature of these limitations appreciated
- care for the 'being' of another is equally important as care for the body but seems a neglected area in MND due to the professional functional emphasis

- a functionalist option is for a new role to be considered for patients who are under severe emotional as well as physical duress like Macmillan nurses for MND patients
- otherwise professionals would need emotional support if they were to offer more to patients

B: Cared For

- emotional limitations on care receipt can lead to further isolation, false expectations and increased suffering for the cared for
- professional emotional care is needed by patients

C: Lay Carers

- lack of emotional support for themselves and their partners can lead to further suffering, isolation and relationship difficulties
- professional emotional care is needed by lay carers

8.5. SITUATED FRIENDSHIP

Emotional support, when offered, was through the vehicle of situated friendship. This involves professionals adjusting their demeanour and values to meet those of the patient; trying to fit in with their life-styles and stance; using emotional labour to be responsive to patient needs and emotions and keeping the focus of care on the patient.

PC3 Responsive friendship
PC5 Responsive friendship to meet patients needs
PC6 Adjusting to patient's stance
PC7 Responding to patients' demeanour
PC9 Responsive close relationship

8.5.1. Implications of category 'Situated friendship'

Situated friendship relationships were desired by clients and supported by the majority of professionals. They tried to fit in with patient life-styles during their visits and they 'emotionally laboured' for the patient's benefit.

In a situated friendship, the focus of care remains squarely with the patient. The patient's needs come first and the professional adapts to the situation of need to deliver the best care they can in this frame.

Practical implications

A: Professional Carers

- a 'situated friendship' offers a relational vehicle for maintaining the focus of care with the cared for
- a situated friendship means the professional adapts to the patients' demeanour and lifestyle but not all professionals are so willing which can then lead to problems
- care for professionals is sought from their colleagues but this care might not always be available
- organised support for professionals was absent i.e. clinical supervision

B: Cared For

- maintaining the focus of care on the cared for offers a sense of valuing and remaining human which is their central value
- when their central value is not realised this can lead to distress and suffering

C: Lay Carers

- if a professional can offer a situated friendship then this could be extended to the lay carer

Philosophical implications

A: Professional Carers

- emotional labour is required to maintain a situated friendship
- a situated friendship may involve suspension of one's own values in order to support the needs and decisions of the cared for
- a situated friendship supports the cared for as a human being first and is linked to their ideals of care

B: Cared For

- a situated friendship from professional carers keeps the primacy of the patient
- it promotes respect for the patient's autonomy
- it maintains the cared for to be valued, as being human

C: Lay Carers

- a situated friendship with professional carers keeps the primacy of the patient but could be extended to lay carers

8.6. LEARNING THROUGH EXPERIENCES TO CARE

The professionals all realised that learning to care is a continuous process and should be implicit in professionals, 'I think if we realise and are open to that, that's helpful' (PC2). They all agreed how experiential learning instructed them not to make assumptions of a patient's level of understanding about MND; to learn from patients by focusing on the patient's ways of being and needs rather than solely their professional perspective; to use themselves in listening, being attentive, empathetic, drawing on personal experiences of care and having an openness to learn about the needs of others; and finally teaching others these ways of knowing in caring for people. This learning clarified their professional knowledge as well as potential for new knowledge.

PC1 Educational imperatives: helping others learn to be cared for
PC2 Openness to learn
PC3 Learning through caring
PC4 Novice learning about care
PC5 Learning through experience
PC6 Learning about MND care
PC7 Learning sensitivity through experience
PC8 Learning through experiences

8.6.1. Implications of category 'Learning through experience to care'

Learning through experience means learning from events with others. This often meant learning from patients and lay carers. The fact that the professionals had an openness to learn and a willingness to accept they do not know all the answers is a significant finding.

The various elements of their learning highlight their motivation to offer the best care they could through responding to the needs of their patients with sensitivity.

They all agreed how experiential learning instructed them not to make assumptions of a patient's level of understanding about MND; to learn from patients by focusing on the patient's ways of being and needs rather than solely their professional perspective; to use themselves in listening, being attentive, empathetic, drawing on personal experiences of care and having an openness to learn about the needs of others; and finally teaching others these ways of knowing in caring for people. This learning clarified their professional knowledge as well as potential for new knowledge.

Practical implications

A: Professional Carers

- learning through practice is a central resource to develop caring practices
- sharing knowledge about symptoms alleviates patient's anxiety
- not knowing is not a preclusion to finding knowledge
- not knowing does not amount to not caring if information is sought
- teaching others what one has learnt experientially about how to be with patients focuses ways of being to students
- reflection on practice is a useful mechanism for learning
- learning about a patient's need for a normality means it can be facilitated by professionals
- learning how to use self is not a well articulated process that needs development with professionals

B: Cared For

- awareness that professionals are learning as well as the cared for may be unnerving on occasions and reassurance may be necessary
- professionals teaching patients has enormous benefits for supporting patients

C: Lay Carers

- teaching lay carers has enormous benefits for patients who wish to remain at home and may boost lay carer confidence
- there is a danger to teaching lay carers, it may pressure them to undertake some practical caring functions that they find disturbing

Philosophical implications

A: Professional Carers

- professionals should recognise development in their professional roles through learning and remain open to potential learning opportunities
- conditions in a person need to be right to learn including, openness and motivation,
- professionals who have values of wanting to offer the best care possible appear highly motivated to learn
- learning from patients can offer opportunities for new ways of being that transcend professional education

B: Cared For

- if professionals put the patients first and listen to them to learn, this is a valuing feature that may have therapeutic implications for patients

C: Lay Carers

- listening to lay carers concerns and learning about problems encountered promotes effective care at home

8.7. CRITICAL NATURE OF TIME

The critical nature of time captures two dimensions; first, professional's recognition of the short time MND patients have left which highlights the urgent need for equipment and services and second, how professionals themselves have little time in their busy working lives to offer the care they want to deliver.

PC3 Temporal urgency of action
PC6 Shortness of time for patients
PC7 Time focus
PC 8 Support for short living time
PC9 Critical nature of time

8.7.1. Implications of category, 'Critical nature of time'

Criticality of time was reinforced by professionals through the imminent death of their patients. Equipment shortages create frustrations and personnel shortages limit time for patient visiting. Ideals are unhelpful if there is no time to put them into practice. The lack of time for patients was identified by the lay carers who felt that professional visits were infrequent and brief.

Practical implications

A: Professional Carers

- time was a critical feature for the cared for and this gave the professionals a sense of urgency
- time spent with each patient was short. Professionals had high workloads which increased their pressure
- care professionals were frustrated with the delivery time for equipment, lack of a central equipment pool meant there were delays for patients
- as non-functional aspects of care are not measured this magnifies pressure on professionals to justify this aspect of their patient interaction

B: Cared For

- busy professionals were unable to offer the time needed, particularly to help with the emotional aspects of their situation
- lack of appropriate equipment due to shortages and bureaucracy caused unnecessary discomfort to MND suffers

C: Lay Carers

- busy professionals were unable to offer the lay carers the time they may need, particularly to help with the emotional aspects of their situation or to establish such a need exited
- extra equipment to meet need would have supported the lay carer as well as the cared for

Philosophical implications

A: Professional Carers

- the importance of being in time was realised by the professionals for the cared for which made them anxious about the impact of organisational constraints

B: Cared For

- not receiving vital equipment and limited interaction with busy professionals impacted on feeling valued. It heightened feelings of vulnerability as they felt unable to complain

C: Lay Carers

- suffering unnecessary delays with equipment and resources, together with infrequent and short contact with professionals were not conducive to positive care delivery

8.8. IMPORTANCE OF INTER-PROFESSIONAL CO-OPERATION

Many professionals can be involved with MND patients but it is unusual for organised inter-professional co-operation, 'It's very much down to whether the local team are interested or not' (PC7). This reference to a local team did not assume one existed for people with neurological problems, it referred to professionals in a catchment area. They would receive referrals for aspects of a persons care on an individual basis.

PC2 Importance of inter-professional communication and co-operation
PC3 Inter-professional co-operation
PC4 Inter-professional liaison
PC5 Importance of professional liaison
PC6 Value of professional liaison
PC8 Liaison with other professionals
PC9 Inter-professional co-operation tensions

8.8.1. Implications of category 'Importance of inter-professional co-operation'

Many professionals become involved with people who have MND. Inter-professional co-operation can be enhanced through a professional team co-ordinator. Case conferences permit them to meet and discuss progress and problems, and include the non-professionals.

Practical implications

A: Professional Carers

- without co-ordination there are no clear boundaries or potential for co-operation. This can lead to duplication omission of function and places further pressures on the clients
- the co-ordinator would be effective in reducing overlap of boundaries between the professionals which is cost and effort effective plus less confusing for the patient
- communication problems are reduced through a co-ordinated team approach involving the clients
- the co-ordinator spends time chasing equipment and resources allowing other professionals to deliver the care

B: Cared For

- a co-ordinator meant one person need be contacted
- problems would be managed by the co-ordinator who could alert the appropriate care professional rather than the client
- a co-ordinated team approach meant the clients could become acquainted with their professional carers and develop desired relationships
- problems could be solved more quickly by a co-ordinated team

C: Lay Carers

- lay carers wanted continuity of carers and co-ordination of professionals particularly to reduce their feeling of technical and professional overload
- co-ordination helps in the organisation of timed visits and interventions
- co-ordination assists the lay carer in their relationship with professionals and allows them to have assistance in selecting the most appropriate advisor for each problem

Philosophical implications

A: Professional Carers

- there was some debate concerning who should be the co-ordinator. Subsequent co-operation illustrates how professionals can accept each others role as complementary rather than in contest. A co-operative way of being is possible
- there remains professional resistance to inter-professional co-operation. This change in working practices needs to be focused to promote quality care and efficient use of resources
- complex patient care demands multidisciplinary interventions and co-operation
- team conferences served to unite the professionals and the specific client team

B: Cared For

- the approach increased a sense of client participation and being valued

C: Lay Carers

- the approach increased a sense of client participation and being valued

8.9. CONTINUUM OF REFLECTIVE THINKING

When asked how the two guided conversation had influenced them, the professional carers gave a range of responses. Three reactions were noted; the first was that they were too busy to think about the conversations; the second was evidence of reflection as the conversation 'made me think what I had done for those people I'm involved with' (PC2).

The third reaction was to wait until they received the transcript and then reviewing the written text it made them more analytical (two participants offered no comments).

PC1 Reflection made thinking time
PC2 Reflective thinking
PC5 Reflection as thought provoker
PC6 Too busy to reflect
PC7 Reflective benefits
PC8 No explicit reflection
PC9 Usefulness of reflection

8.9.1. Implications of category 'Continuum of reflective thinking'

The busy nature of professional life certainly seems to be a barrier to reflective thinking. The evidence suggests reflection is useful and written reflection can be supportive in busy lives. Positive strategies for practice delivery can be identified.

Practical implications

A: Professional Carers

- the busy nature of professional life appears to be a barrier to considering events of the day or feelings and attitudes
- for the majority, talking about the care they offer and its effects on them and their patients has a positive learning outcome
- non-reflective practitioners can lead to stale practice
- written reflective accounts can help stimulate reflective thinking

Philosophical implications

A: Professional Carers

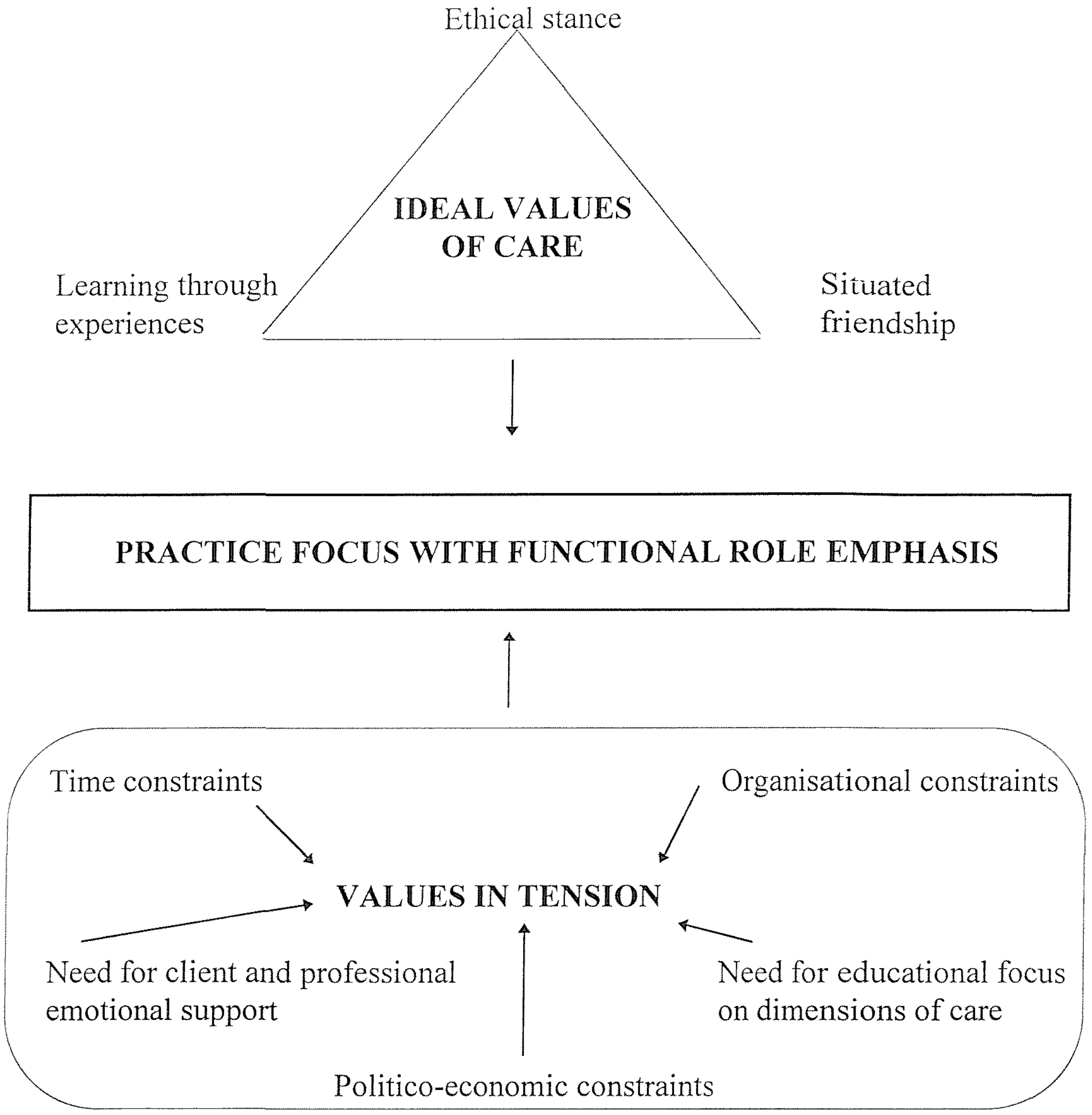
- being too busy prevents consideration and so may lead to automatic practice with little scope for learning.
- reflection needs to be a valued activity to being a professional
- adopting reflection in work practices is considered important to support professionals in their stressful roles

8.10. PROFESSIONAL CARER VALUE OF CARE MODEL

The professional participants were faced with an uncertain time frame to care for a terminal patient with multiple physical disabilities. They appreciated the debilitating effects of MND but appeared in a state of tension with their ideal values as professional carers and the constraining realities on their practice which was realised in practice through prioritising their functional roles (see figure 12).

The professional participants' ideal values guided an ethical stance towards clients. It was actualised through a situated friendship and was developed by learning through experience. However, these attributes of the ideal were always variable in practice and not consistently practised. The main limitations on their practice developed a situation of values-in-tension for the professionals. The strong influence of these tensions forced them to practice with a predominantly functional emphasis, only drawing on their ideals when possible.

Figure 12. Professional carer value of care model



It can be argued that professionals who do not appreciate a situation of 'values-in-tension' in relation to the 'ideals values' may practice their functional role as an absolute. Indeed, the values-in-tension may dominate professionals whereby their practice responds to the limitations thereby offering the worst possible care delivery. This worst possible scenario would lead to a complete absence of emotional care for clients coupled with no educational or organisational support for the professional. This would mean working within the economic, personnel and time limitations with the practice focus solely with a functional emphasis.

8.11. SUMMARY OF CHAPTER

This chapter has presented the major findings from the professional carer participants. Evidence has been offered to support the constructed categories with structural and values based models of professional care. Acknowledging that the participants offered a good practice example to clients permits consideration of the best and worst scenarios in terms of care delivery as there is a clear tension in professionals' ideals of care and their reality. This leaves their dominant stance in the world of functional delivery. It is now important to compare the three participant groups to gain insight into the similarities and differences between care receipt and care delivery.

CHAPTER 9: THE LEARNING RECOMMENDATIONS AND CONCEPTUAL MODEL

9.1. INTRODUCTION

This chapter responds to the research question by revealing 'gaps and matches' between the values of lay and professional carers which can affect care delivery and receipt. It also presents the constructed conceptual model of lay and professional care.

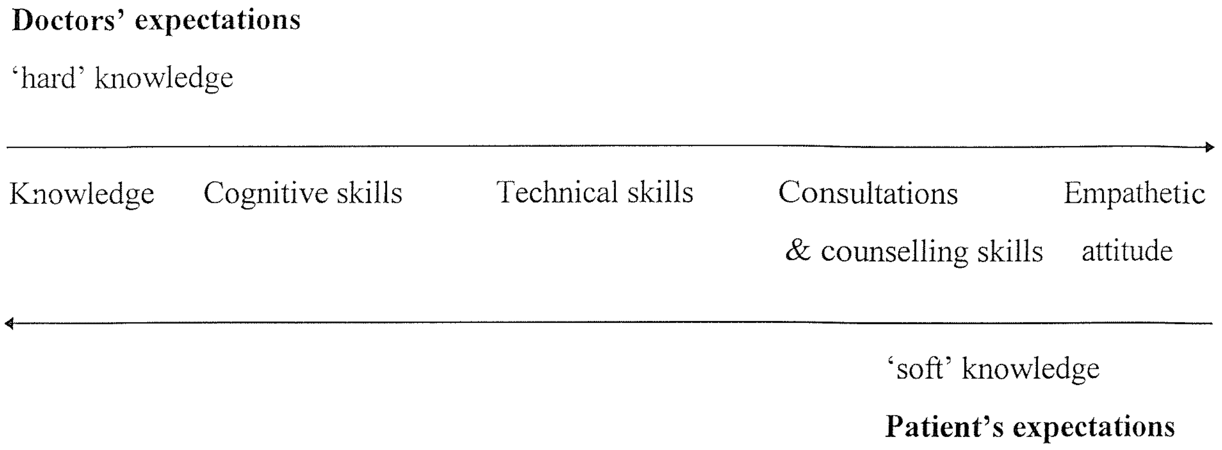
The value 'gaps' significantly outweigh the 'matches' with most alignment being present between the MND and LC participants and most divergence between the lay and professional participants. The 'gaps' are perceived deficits of care delivery arising from the professional world. This suggests their detachment from the experience of illness and living with MND. Their 'matches' locate their strengths in the functional interventions for physical decline.

The individual models of care (chapter 6,7,8) have captured the different value bases of the three participant groups. The MND and LC models reflect their existential experiences. MND participants value being treated as human beings and LC participants value the love for their partner which supports them in suffering whilst adapting to change and loss. The PC model reflects their tension in practice where a dominant value for functional intervention prevails, albeit in conflict when engaging with clients' experiences. Some professionals attempt to practice their ideal values of care but these become marginalised by the identified values-in-tension. The obvious question arising is 'Why is the human-existential value of care found to be of secondary importance in MND care delivery when it appears primary in client values? This stimulates other enquiry areas of Why do these different stances exist? Why is the experience of illness neglected by professionals? Why is the professional focus primarily on the 'function' of the person rather than the processes the person is experiencing?

Curzen (1991) examined doctor's and patient's 'priorities of expectation' which he presents as the contrast between valuing 'hard' or 'soft' knowledge (see figure 13). Curzen links professional educational priorities to patient expectations and concludes that the 'order of priorities in which specialists put their educational agendas are in contrast to the expectations which their patients have of them' (Curzen 1991:14). Although it can be argued that this incompatibility lies in the quest for physical cures, the person has always been the focus for cure.

The imbalance in professional practice must therefore lie with the influential philosophical belief that humans are biomedical objects that can be 'fixed' rather than people who have holistic needs.

Figure 13. Doctor's and patient's priorities of expectations (Curzen 1991)



Doctors' expectations
'hard' knowledge

Knowledge | Cognitive skills | Technical skills | Consultations & counselling skills | Empathetic attitude

'soft' knowledge
Patient's expectations

Professional learning recommendations are developed in an attempt to redress this imbalance but a fundamental influence on values appears to be one of situatedness or stance. The identified 'gaps' between the values of lay and professional carers offers evidence for developing the learning recommendations but Bourdieu's (1980) theory of practice can be harnessed to consider the stances of the three participant groups, to unravel the values of their worlds with a view to extend horizons of understanding.

The study's evidence and Curzon's mapping of priorities suggests that if improvements in care delivery are the goal, initial priority for change can be justified as resting with the professional agenda. They are regarded as the specifically educated and 'legitimate' carers in society. However, another dimension to consider is how much responsibility for care delivery should be assumed by the cared for and lay carers? In this study their voices have been heard and documented, their central values exposed and their needs verified. They are viewed as the recipients of care but exhibit learning potential and have the experiential knowledge of being cared for and offering care. Questions arise such as, 'How active should they be in directing their own care provision or their receipt of care?' 'What responsibilities should they assume in this process?' 'Should they be involved in education and training measures?'

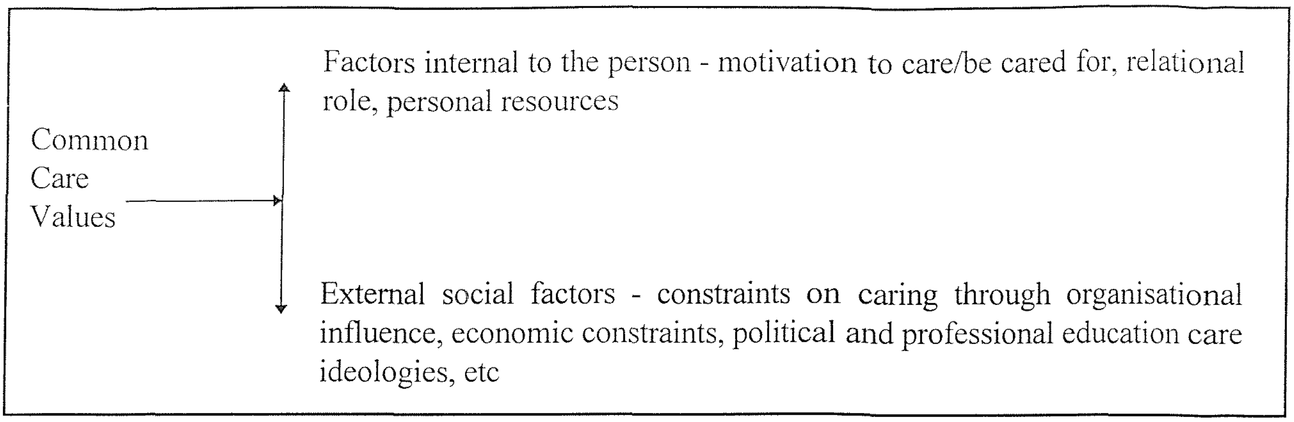
'What learning recommendations should they be responsive to and who should organise their education?' 'Should responsibility for holistic care solely rest with professionals?'

Some MND and LC participants turned to the MNDA for learning about the physical and emotional aspects of MND. The wealth of knowledge in these two domains was praised but there was no evidence to substantiate the MNDA was considered part of any multi-disciplinary team. Some lay participants voiced their dissatisfaction with the care delivery from professionals and acted. Clients chose not to attend a consultant's clinics due to a perceived poor attitude and they located an alternative practitioner nearer to their own value base. This option may not always be possible and when clients are dissatisfied, there is usually little opportunity for re-dress. This situation has a parallel with professionals. When resources are insufficient to practice as they judge, there is little opportunity for changing the circumstances. This interplay between the personal and the external factors affecting care values requires further consideration and sets the scene for entering into Bourdieu's (1980) theory of practice (section 9.5).

9.2. INFLUENCE OF INTERNAL AND EXTERNAL FACTORS ON VALUES OF CARE

Internal and external factors can be identified which influence values of care. Internally, the three groups of participants expressed a positive stance to care. They demonstrated common care values believing in ethical values and they mainly practised with compassion and kindness. Internal factors may affect their practise including personal characteristics and resources, individual motivation, relationship potential and their own situation. Externally, factors were experienced through the influence of available economic resources, organisational priorities and the over-riding professional focus on practical care over emotional provision. These external factors affect both clients and professionals. Clients may suffer deficits in their care receipt and professionals suffer tensions between their personal values and organisational values of care. This can create frustration and pressure in care professionals. It also creates a situation of further suffering for the clients. From the restrictions on professionals, clients may not receive essential equipment and regular visits from professionals. They may suffer from unfulfilled emotional needs in coping with the extreme condition of MND. Figure 14 summarises the internal and external influences on values.

Figure 14. Factors influencing values and their effects on the delivery of care



The existence of common care values, influenced by external and internal factors, supports the conclusion that values are dynamic. They can be learnt, practised and contextually responsive. Within this view, education, ideology, experiential situations and organisational directives are all influential to values-in-use. Professional carers are constantly exposed to external values whereas patients and lay carers enter the care world without formal consideration.

If we accept Heidegger's premise that care is 'ontological in that it constitutes one as human' (Roach 1992:14) then we can accept that care is a human trait. An ontological capacity for care invokes the valuation and practice of ethical values. The 'natural' existence of these ethical caring values can be defended from a socio-biological perspective as 'having the capacity to act morally, is favoured by evolutionary biology' (Thomas 1985:123). An explanation for differences in practices or action of care can be that people are exposed to and learn different care values. Each person's contextual situatedness, or 'throwness' using Heidegger's term, is a route for learning about care values, as one tries to make sense of oneself within one's surroundings. The learning of these care values therefore influences one's caring practice. If we apply the concept of throwness to the three participant groups, they each find themselves on a different side of the caring triangle, a different perspective on the situation of being in the world of care. It is not surprising that they emerge with three variations of care values and three variations of caring behaviour.

A person threatened by MND is 'thrown out' of their normal existence and 'into' an unknown world of being cared for. Vulnerability, the threat of immobility and death creates personal stress and may cause value modification as the person struggles to adapt to their new situation. This study exemplifies how the 'cared for' experience many tensions and struggles; losing personal control, becoming vulnerable to others whilst facing their own mortality in an increasing isolated and silent world. Their values of being human may have included self-determination and autonomy and their caring values guide their actions to compassion and kindness towards others. As their physical abilities become jeopardised and their interaction skills diminish they have to learn to be cared for. This involves finding gratitude, tolerance and patience to cope with their new circumstances. This does not mean their personal values would have changed if they had remained without MND but within its world their new situation demands prioritisation of adaptive or 'responsive contextual values'. The caring values they desire to receive incorporate their original values of being treated as a human being, receiving sensitivity and respect for their autonomy despite their neurological deficits and impending death.

Lay carers are also 'thrown out' of their previous world and 'into' an unknown world of caring. They experience tensions that may influence their ideal values. Their personal resources to care are challenged as is the love and liking they have for their ill partner. When personal resources exist and love is strong, being a lay carer is hard both physically and emotionally and therefore a challenge to ethical and safe practice. If personal resources are limited and love unsure then the ethical and practical processes become harder. MND is a condition that robs its victim of communication, an identified ingredient of being human. The evidence indicates how loss of communication affects carers in their concept of the patient as being human and therefore warranting human receipt of caring values.

Professional carers are already 'in' a world of care, albeit also of cure. It is their chosen occupational purpose and they have undergone an educational programme to prepare them to practice its taught philosophies and skills. The individual may hold caring values as important but there are situations where personal care values may be over-ridden by professional and organisational values which have been formally learnt. Professionals are faced with the tradition of functionalism and have to work through changing political ideological stances. These currently value market forces with a change in viewing health as a right to a commodity. At this macro level, there is the risk of dissonance between ideal and responsive contextual values.

Jarvis (1997:3) reminds us, 'values are only realised in practice' which puts professionals in tension and strains their human caring values and capacities. Functional priorities become the minimum line within the limited time for each patient. They may experience economic constraints which undermine their recommendations for providing essential equipment to patients, they may suffer organisational apathy in terms of desiring inter-professional co-operation and face professional and managerial constraints for using facilities for the dying such as hospices. [In this study hospice provision was not available for people with MND].

Why is care not actualised through its ideals? The influence of market forces, measurable outcomes, personal autonomy and personal responsibility, seems to neglect community. This neglect dilutes ontological processes and philosophical imperatives in care to focus on practical outputs, interpreted through functional skills. Professional carers are most influenced by these developments in terms of care delivery and clients are most influenced in terms of care receipt. It can be argued that professional carers are attracted into caring professions to actualise their personal human orientated caring values. They are then faced with the reality of the external factors and find personal values are considered second class.

Professional education and care organisational ideology promotes practitioners to primarily meet pragmatic/functional values. Expectations are that the type of person attracted to care professions will bring the process qualities but these need no further nurturing or valuing. Functional visible outcomes of care are given an external legitimacy whereas human interaction aspects are not externally recognised. Professionals have to re-learn new values of care which focus on the organisational/economic/professional priorities and lessen the human caring values. This is an unbalanced situation not desired by the cared for, lay carers or even care professionals themselves.

Learning is a natural process. 'It is the basic driving force through which the human essence emerges….. It is fundamental to Being itself… but it also requires the presence of the social' (Jarvis 1997:65). He suggests learning itself is amoral because it is a natural phenomenon. However, the type of person one becomes as a result of learning is a moral question. What one learns is therefore the pivot.

The content of one's learning is usually derived from one's society or culture, and responds to the dominant values. As Jarvis (1987:67) states 'selection from culture is always an act of power, and those who claim the right to define what should be learned exercise power which always contains moral intentions'.

This statement highlights the importance of recognising external factors. Traditionally these have been dictated through professional ideology and education, economic and political factors. In our current political climate of 'modernisation' (Milburn 1999), the guiding emphasis is changing to be responsive to clients. This change may support a refreshing equilibrium in care priorities for disabling diseases, which can be led by revising care educational content. If educational content is supported in this quest it can more than influence the students but support directional change for care provision and prioritisation in societal and cultural terms.

The evidence in this study supports this stance. The voices of the cared for and lay carers have been heard in the world of MND. They can be harnessed to steer potential developments towards this 'modernisation' drive in care provision. Therefore, the first task is to map out the practical and philosophical implications from the group categories. Gap and matches in these dimensions can be identified to locate professional carer learning recommendations. The second task is to apply Bourdieu's (1980) general theory of practice to the three stances of the participant groups in order to shed light on the interplay between experience and context.

9.3. MAPPING THE PRACTICAL AND PHILOSOPHICAL 'GAPS AND MATCHES'

Care can theoretically be separated into practical action and thoughtful being. The mapping starts with this theoretical distinction through identifying practical and philosophical 'gaps and matches' between the three participant groups. In reality, the two distinctions should occur simultaneously; that is both 'practices' should be in union. Practical interventions should try to make the practical aspects of being more tolerable for people with MND and their lay carers. Thoughtful being should focus the patient (and lay carers) as persons, for whom every interaction and practical intervention is a relational moral stance. Therefore, the professional learning recommendations do not reflect this distinction as the practical/philosophical division is dissolved.

The mapping is approached by examining all the constructed categories. The lead is taken by those constructed from the MND participants. Care received and care delivered are examined through comparing a MND category triad of implications with evidence from the LC and PC categorical triad implications. A map of categories across the three groups of participants, is presented in table 18.

Five similar categories are evident across all three groups and they are identified in **bold**; struggle with increasing loss of control, temporal issues, learning to be cared for, strengths and limitations of received care and reflection. On one occasion, three categories from the professional carer group are aligned with single categories from the MND and LC groups ('strengths and limitations of professionals').

When similarities amongst the three groups does not occur, two approaches are taken: where only MND and LC are similar this is identified in *italics* and when an individual category has no other comparative category in a group, this is indicated with an x. This leaves two occasions when one group is the sole category, the 'ideals of care' from the professional carers and 'preparing for loss' from the lay carers. In these instances, examples of divergence and convergence from other group categorical implications are sought.

The starting point for this mapping lies with the MND category of 'existential shock.' Divergent/convergent aspects are located through first examining the LC category 'De-stabilising impact' and then the remaining categorical implications from the LC and PC findings. Gaps in the practical provision and matches in the practical provision are initially identified followed by gaps and matches in the philosophical provision. The gap and match provision refers either to the action of doing (practical) or to the action of being (philosophical).

Although ordering of this comparison is using the MND categories as the pivot, it is interesting to reflect on the temporal priorities of categories from the three groups and to appreciate how again there is most alignment between the MND and lay carers in that they both experience shock, need to make meaning about their situation as they struggle with their increasing demands through loss of control or the need to adjust their lives. Whereas the professional carers begin talking about their strengths, ideals and limitations at first and this roots them as outsiders, observers who have caring potential but without the same level of involvement, experience or change potential.

These eleven groupings are considered in turn. Two categories are illustrated with the full process of this mapping (existential shock and learning to be cared for) as the first represents a joint MND and LC concern but without a PC category and the second offers an account where three participant groups have a similar category.

The remaining outcomes are presented with the 'gap and match' summary outcomes, their full processes are documented in appendix 14.

Table 18. Comparison of categories across the three groups

MND (9)	LC (10)	PC (8)
Existential shock	*De-stabilising impact of impending death of spouse*	x
Importance of creating meaning	*Searching for answers*	x
x	x	Ideals of care
Struggle with increasing loss of control	**Forced life changes in caring for another**	**Importance of inter-professional co-operation**
Temporal realisations	**Temporal realisations**	**Critical nature of time**
Learning to be cared for	**Learning through caring**	**Learning through experience to care**
Changing relationships	*The vulnerability of being a carer*	x
Dynamic normality	*The false normality*	x
Strengths and limitations of received care	**Strengths and limitations of professionals**	**Strengths of professional role** **Role limitations** **Situated friendship**
x	Preparing for loss	x
Reality unmasked through reflection	**Reflection highlights reality**	**Continuum of reflective thinking**

9.3.1. 'EXISTENTIAL SHOCK'

This MND category has a comparable LC category, 'De-stabilising impact of impending death of spouse', but no comparable PC category. However on examining the PC practical and philosophical implications, supportive evidence can be taken from four PC categories: 'learning through experience to care', 'ideals of care', 'situated friendship' and 'importance of inter-professional communication'.

MND practical implications from 'Existential Shock'

A: Cared for

- need for a diagnosis to explain symptoms
- need for early referral to a range of professional agencies to reassure patients that practical help is available
- need for early contact potential to the voluntary agency, MNDA

Divergence/Convergence analysis

The diagnosis was offered to all participants but it is acknowledged that MND is not easy to diagnose. Development of a clear definitive test would prove invaluable but medical research would need to identify and conduct such a process.

Immediate referral to a range of professionals was achieved but sometimes it was too ill-focused. Often many professionals would arrive on a person's doorstep, which would prove confusing as their boundaries were uncertain, particularly if there is no inter-disciplinary co-operation. Establishment of a designated 'MND neurological team' would assist in this predicament with a lead co-ordinator who could perform an initial and on-going assessment of patient need throughout the disease trajectory.

MNDA literature was haphazardly given to newly diagnosed patients. This practice needs to be formalised with the emphasis on patient choice to contact the voluntary body.

LC practical implications from 'Existential Shock'

B: Lay Carers

- need for practical help to support their spouses with this shock - someone to talk with spouse, key worker to set up physical services
- need help themselves to cope with this shock - someone to talk with them in addition to their partner

Divergence/Convergence analysis

The absence of a key worker or co-ordinator meant the lay carer often had to deal with the number of professionals carers who arrived offering practical interventions. However, there was an absence of explicit support for lay carers to help them help themselves and support their MND partner. Individual assessment options were available from social services but in no cases were these realised. No health care assessment was explicitly available in terms of their own fitness to perform physical caring activities e.g. lifting etc. A GP could offer this service as a regular 'carers health check' where physical and emotional strains could be discussed.

PC practical implications from 'Existential Shock'

C: Professional Carers

- need for a clear protocol for searching/telling the diagnosis of MND
- need to plan timing when telling the diagnosis to allow for emotional support to be available (e.g. relative)
- educational support to help them offer news of MND sensitively
- need to develop strategies to offer support to patients/lay carers during and after the telling
- need to promote continuity of experienced and interested care professionals who can be with the patient throughout the disease trajectory

Divergence/Convergence analysis

The above PC implications are all divergent aspects that need consideration to improve delivery of care.

Table 19. 'Existential shock' practical gaps and matches

Gaps in practical (doing) provision provision	*Match in practical*
• lack of a definitive diagnostic test for MND	diagnoses are offered
• need for learning improvements in 'telling bad news' and following up people who have received it	
• lack of a 'community neurological team' with a lead co-ordinator of professionals	some teams are organised
• lack of protocol for MNDA literature distribution	this can occur but is haphazard
• absence of specific lay carer support/physical assessment	this can occur but is haphazard

MND Philosophical implications/Implications on ways of 'being' with Existential shock

A: Cared For

- need for a sensitive teller of the diagnosis
- reassurance that being vulnerable and frightened is 'normal'
- need for patients and others to understand the existential shock concept and the situatedness of the person newly diagnosed with MND
- need for others to help share the shock
- need for something to 'fight against', goals can help reduce the sense of powerlessness to a sense of potentiality

Divergence/Convergence analysis

No evidence of perceived sensitive tellers of diagnosis

No specific protocol/will to emotionally support the patient through the telling or aftermath of the diagnosis

No explicit realisation in PC's of the shock element of the diagnostic news or ways of supporting the patient at this crisis moment to offer some sense of optimism for future support

No path to follow for the patient, no guidelines or expectations of the future support offered which leaves them in a state of unknown which further increases existential shock

LC Philosophical implications/Implications on ways of 'being' with Existential shock

B: Lay Carers

- awareness of the threat to 'being' created by MND
- acceptance of their partner's shock, its effects and the prospect of an early death
- support for their own shock, its effects and the prospect of being alone

Divergence/Convergence analysis

No clear external professional help to support lay carers to come to terms with the diagnosis and support them in supporting their partner with its effects. Lay carers may be too distressed to be able to help their partner in the first instance or have few personal resources to draw on in this domain. They also have to begin searching for a new way of being.

PC Philosophical implications/Implications on ways of 'being' with Existential shock

C: Professional carers
- absence of awareness of existential shock of newly diagnosed people may lead to insensitivity in this domain
- lack of sensitivity when PC's are engaging with a 'dying' patient and his or her family
- need for increased understanding about the impact of such a diagnosis on a persons life
- need for support themselves to actualise client support

Divergence/Convergence analysis

No sense of existential awareness of the ontological impact of the diagnostic implications. Some evidence of PC's learning ontological implications of the disease impact in 'learning through experience to care'. Not all ontological experiences were communicated to them by the MND and LC's, they can remain invisible but the PC's do not actively try to discover them.

No evidence of PC's viewing people with MND as 'dying patients' which would be found in cancer patients and appropriate different values of care . Some co-ordination approaches are in existence as actualised by enlightened professionals but these are not the norm.

The absence of a co-ordinator/key worker in the telling of the diagnosis ensures care delivery is severed at the moment of greatest impact, sends message of holism not being a reality value practised by care professionals. Professionals in 'reflection' category identify that in practice they have little emotional support for themselves which may reduce their insight or willingness to 'risk' emotionally interacting with patients.

Table 20. 'Existential shock' philosophical gaps and matches

Gaps in philosophical (ways of being) provision	*Match in philosophical provision*
• Lack of existential awareness, ontological impact of the diagnostic/existential shock implications for a person/LC • Lack of sensitive tellers of diagnosis • Lack of inter-disciplinary protocol/will to emotionally support the patient/LC through the telling or aftermath of the diagnosis • Lack of inter-disciplinary co-operation values to offer seamless care • Lack of emotional support for professionals to help them help others	None collectively

9.3.2. 'LEARNING TO BE CARED FOR'

All three participant groups had a sense of learning through care and all these categories and perspectives are drawn on in this section.

MND perspective of practical implications from 'Learning to be cared for'

A: Cared For

- being cared for is disliked. A continual tension in their area can create more exhaustion and frustration
- accepting the disease and therefore the caring may need some time
- adjustments will need to be made to many practical aspects of life and these need to be considered, debated and when possible agreed with the recipient
- consistency of all carers is desired
- awareness of the pressures on lay carers, as caring is hard work may promote acceptance of social carers
- communication difficulties exacerbate feelings of vulnerability and make acceptance of caring harder, particularly if carers change

Divergence/Convergence

Learning anything is a process and in the case of MND, the process is dynamic. Once something is learnt, such as being handled, the disability gathers momentum and a new way of dealing with the practical aspect of immobility needs to be learnt. In the sense of cumulatively being physically dependent, learning to cope with disability and the associated invasive effects of others was the constant. It seems that the sense of self is so linked to ones physical abilities. Continuity of carers allow the integrity of that sense of self to be maintained as carers from the beginning will always be aware of the person as they are reduced to immobility and poor communication. The history of knowing the person before the physical shut-down is regarded as essential to the cared for and is implicit in the lay carers. The professional carers however may rotate their interaction with the cared for, not have a fine tuned sense of use of self in the process of caring. Experienced care professionals offer an enhanced level of service and support for clients whereas inexperienced professionals can cause disproportionate distress as they are insufficiently skilled to offer support.

LC perspective of practical implications from 'Learning to be cared for'

B: Lay Carers

- resistance of social carers may be worse if personnel changes are frequent
- 'supervision' by lay carers of contact with social/professional carers may be supportive for partners who have communication difficulties
- emotional frustrations may be met with increasing loss of independence by their partner
- the link between accepting the disease and caring may need some time
- adjustments will need to be made to many practical aspects of life and these need to be considered, debated and appropriate action made with choice remaining with the cared for

Divergence/Convergence

Learning to care for lay carers means acquiring many new practical skills and being challenged emotionally. Practical support was offered by the professionals in many aspects but they still needed to refine their problem-solving skills. The personal adjustments of the lay carers were expected rather than supported.

PC perspective of practical implications from 'Learning to be cared for'

C: Professional Carers

- patients experience anxieties concerning challenges to privacy , this needs every effort to reduce these challenges
- promote continuity of care at all times - team approach important
- when there are communication challenges, always speak to the patient but involve the lay carer to help interpret so the cared for is always heard
- lay carers need support with practical interventions of learning care, in addition to the patient

Divergence/Convergence

Lack of continuity of carers in many instances led to increased suffering for the cared for and lay carers. Although professionals were open to learning from clients and lay carers this usually involved a cost to their clients and lay carers. A team approach would facilitate reduction of this issue

Table 21. 'Learning to be cared for' practical gaps and matches

Gaps in practical (doing) provision	*Match in practical provision*
• Continuity of carers variable	Continuity of carers variable
• Experienced team of professionals would assist in learning through care	Practical teaching offered to lay carers for skills work

MND Philosophical implications of being in learning to be cared for

A: Cared For

- accepting care may be linked with accepting MND
- knowledge that adjusting and learning to care are 'normal' features of having a disabling disease may help in this phase of a change of 'being'
- challenges to privacy can be debated with carers to develop strategies to minimise them
- vulnerability and loss of control are inevitable outcomes of being cared for; they are a shift in one's state of being
- awareness of the stress on partners in caring is important but this needs to be balanced with the patient's need to preserve their 'voice'
- communication difficulties can render the patient more out of control and vulnerable as they cannot express themselves. In preparation for this and to reduce these feelings, set up a written introduction of yourself, your preferences and dislikes in many situations with a range of audiences.

Divergence/Convergence

Learning to be cared for involves many adjustments in one's sense of self. It is a sense of becoming through adversity as a new sense of self is continually being discovered in alien territory. The learning is most acute with the cared for and lay carers as this is not their world so their sense of being is most challenged. In addition, the cared for have the double loop of learning to be cared for as they learn to 'leave life'. The lay carers have the double loop of learning to care and learning to be left. Vulnerability, loss of control, emotional challenges and a shift in one's sense of known being are all part of the learning. Communication difficulties render the cared for with the ultimate challenge - how to express themselves without movement or voice. The challenged also have to learn how to respond to this variable predicament.

LC Philosophical implications of being in learning to be cared for

B: Lay carers

- awareness that partners' acceptance of care may be linked with accepting MND
- the stress of caring for a partner may be enhanced if they resist your interventions. Need to discuss ways of being patients prefer
- need for awareness and sensitivity of partner's anxiety concerning challenges to privacy with effort made to reduce these challenges
- as communication difficulties become more profound your partners may withdraw. Try and plan some form of new communication before this happens
- awareness that social isolation occurs as patient communication decreases

Divergence/Convergence

The gradient of the learning to care curve is almost as steep for the lay carers as it is for the cared for. There was no explicit link between accepting care and accepting death made by the lay carers but the most alignment between carer and lay carer arose when there was open discussion between them on ways of caring. When discussion was not forthcoming, communication was threatened before the physical embargo. It seems in learning from each other, communication is the vital key to move forward together

PC Philosophical implications of being in learning to be cared for

C: Professional carers

- need awareness that for patients to accept care may be linked with accepting MND
- need for awareness that patients are being forced to learn how to be cared for. It is a threat to them (if they react against it, it is not necessarily personal)
- lay carers will be exhausted by the effort of caring and have their own needs
- communication challenges do not remove the person from the caring focus

Divergence/Convergence

Professionals who have motivation to care are generally more successful from the patient's perspective, as they are motivated to learn about their patients and the ways of being in relation to the care offered. Linking with the lay carer also offers that professional carer alternative insights into the needs of patients and lay carers. Relational attempts by professionals offer a positive sense to the clients and lay carers and allows more insight into the 'real' world of their clients. This allows them more opportunity for successful intervention at all levels.

Table 22. 'Learning to be cared for' philosophical gaps and matches

Gaps in philosophical (ways of being) provision	*Match in philosophical provision*
• Professional's lack of explicit awareness of the challenge of MND to a person's sense of self. Recognition of vulnerability, loss of control, emotional challenges, shift in one's sense of known being and own learning curve seem absent	
• No clear appreciation from carers of link between accepting care and accepting death	
• No constancy in relational attempts with clients to understand the effects on their being of their learning curve	Some attempts made in relational learning

The remainder of the categories with their associated gaps and matches are located in appendix 14 with a listing of the gaps and matches in appendix 15. Section 9.3.3. offers a summary of the practico-philosophical gaps and matches which link with the professional learning recommendations as presented in section 9.4.

9.3.3. SUMMARY OF THE PRACTICO-PHILOSOPHICAL GAPS AND MATCHES

The gaps in care delivery (23 items) strongly outweigh the matches (4 items). This indicates that there is a serious deficit in the professional delivery, according to the cared for and lay carers in the this study. These are presented in tables 23-25.

Table 23. The Practico-Philosophical Matches

1. Functional interventions of the professional disciplines are well received by the cared for and lay carers
2. Teaching by professionals to lay and the cared for is appreciated and positively received
3. Biomedical ethics upheld respect for autonomy of individuals, a compatible value to MND and lay carer
4. Although there is limited evidence of relational attempts in the form of a situated friendship between professionals and clients, when this does occur (MND3/LC3) it is valued and considered successful by people with MND and lay carers

Table 24. The Practico-Philosophical Gaps 1-11

1. Clients value a more proactive stance on functional care by professionals. Need for planning for independence strategies rather than meeting current need or historic need
2. The cared for require a greater sense of control over their care which needs PC's to facilitate
3. A sense of dynamic normality needs promoting and supporting in the lives of the cared for and lay carers which PC's need to be aware and be responsive to this requirement
4. A need for lay carers to receive specific support in the emotional and practical dimensions
5. Specific equipment needs to be available within short time-frames to support people with MND (e.g. light-writers, customised wheelchairs etc)
6. Written information and immediate access to people with experience of MND is required by clients
7. Inter-professional co-operation needs to be widespread and normal practice to reduce repetition or omission of care delivery
8. Multi-disciplinary neurological teams are desired by the clients
9. Lack of access to hospice care for people with MND removes them from a valuable care resource
10. Need for existential awareness from PC's of the experience of being ill, lay caring and the effects of MND on the person
11. Need to redress the imbalance in ethical considerations. Too much emphasis on biomedical ethics with negligence of ontological and relational aspects of human relations

Table 25. The Practico-Philosophical Gaps 12-23

12. Lack of support for PC's to be open and responsive to help cope with caring for people in extremis. Some pockets of clinical supervision but they mainly rely on informal support networks

13. Lack of situated friendships between PC and the cared for.

14. Lack of realisation amongst PC's of the importance of relationship with others in being - supporting being - reflecting being- to facilitate the desired situated friendship mode

15. Lack of time for PC's to develop relationship or knowledge of people with MND and their lay carers

16. Lack of holistic care for the cared for

17. Mutual vulnerability of MND and LC not appreciated or supported by PC's

18. Neglect of MND and LC's sense of being a person and PC's knowing them as people

19. PC's neglect of unification between the practico-philosophical aspects of care, the majority divided them whereas the need was for unification

20. Suffering and loneliness of MND and LC's not addressed

21. Absence of any preparation for death counselling

22. No clear professional role to focus on lay carer or to offer grief and bereavement counselling

23. No clear professional role devoted to being with the cared for on their journey through terminal illness

9.4. PROFESSIONAL CARER LEARNING RECOMMENDATIONS

The learning recommendations are drawn from the gaps and matches identified from the eleven categories. The full listings are presented in appendix 14 with some practical recommendations included to inform development of external factors influencing care delivery.

A total of 40 learning recommendations are identified and Table 26 groups them into four specific educational areas which could be incorporated into professional carer curricula. The four areas are presented in this section with their associated learning recommendations.

Table 26. **Four educational areas of professional carer learning recommendations**

Philosophical/Ontological
  Practico- Philosophical values of care
  Ontological aspects

Relational
  Inter-professional co-operation in care
  Relational knowledge and experience

Ethical
  Biomedical and caring ethics
  Communication and listening skills

Trajectory of illness
  Concepts of change in terminal disability
  Aspects of terminal care
  Time management/prioritisation

9.4.1. Philosophical/Ontological Learning Recommendations

Practico- Philosophical values of care

1. Continue developing functional skills with professionals but in tandem with philosophical debates regarding what constitutes being human

2. To develop understanding of the complexity and diversity of care needs - incorporate perceptions and experiences of care from experiential and theoretical domains

3. Introduce existential issues concerned with being human - application of philosophical orientations to being human in illness, disability, suffering, care and health

Ontological

Self

1. To encourage personal growth, to learn about themselves as people, their being in the world, and how they can receive support for their own ontological needs in order to develop insight and practice abilities in helping others

2. To introduce reflective time into curricula with the purpose of structured reflection on their practice with clients to consider relational interactions to raise their self-awareness and sensitivity to clients

3. To develop reflective skills as a vehicle to facilitate clients reflections on their situations, with the main purpose of shifting the care focus from mainly physical aspects

4. To facilitate practitioners to actively engage in a supportive strategy for their needs such as clinical supervision

5. To discuss concepts such as emotional labour in professional care

Others

1. To appreciate the impact of diagnosis on the being of a person. Promotion of sensitivity in telling bad news. Listening to stories from patients about how they were told their diagnoses and its impact is a useful strategy to illustrate ontological implications.

2. Appreciation of interface between hope and goals in health and illness situations

3. Develop understanding about self identify and the physical-emotional-intellectual challenges when under existential threat and/or duress

4. Appreciate the link in physical disability between accepting care and accepting one's death

5. Understand how accepting caring is a steep learning curve which the cared for have to accept

6. To learn how vulnerable lay carers can be and holistic real challenges faced by them

7. To explore the concept of embodied vulnerability, as experienced by the cared for and lay carers

9.4.2. Relational Learning Recommendations

Inter-professional co-operation in care

1. Promote multi-disciplinary curricula development for shared learning arrangements in undergraduate/pre-registration preparation programmes and continuing professional development

2. Encourage inter-professional co-operation in practice through virtual case conferences and include voluntary agencies (such as MNDA).

3. Increase awareness of the role of voluntary agencies as supportive centres for information and advice

Relational knowledge and experience

1. Appreciate how terminal disease affects family relationships and how best to help in this situation

2. Develop understanding of patient-professional relationship in terminal disability

3. Explore the concept of situated friendship, ways of interaction and developing therapeutic relationships with the cared for and lay carer

4. To learn ways of knowing another as an ingredient of a therapeutic professional-client relationship

5. To learn about the dynamics of relationships under duress

9.4.3. Ethical Learning Recommendations

Biomedical and caring ethics

1. Continue with biomedical ethical principles as a curriculum requirement for practice.

2. Formally introduce the caring ethics of Gilligan (1982) and Noddings (1984) into curricula. Formal declaration of this knowledge in educational curriculum could make them 'legitimate' and 'respectable' viewpoints and contribute to a broader ethical emphasis on care.

3. Open horizons and values to appreciate their influences on care delivery

4. Open students horizons to external values and horizons to appreciate their influences on care delivery

5. Open students horizons to patient and lay carer's values and experiences so professionals can engage more productively with them - read autobiographical accounts of being ill and cared for discussion, engage in the culture of lay care

6. Appreciate the importance of self-determination and personal control for patients to encourage professionals to facilitate this aspect of care if it is required by patients

Communication and listening skills

1. To learn about the value of listening and being available to hear about suffering rather than having to be action orientated all the time - to learn how hearing about another suffering can be therapeutic in itself

2. To further develop listening skills

3. To develop sensitive inquiry skills to establish clients concerns and coping strategies

4. Explore a diversity of communication approaches to facilitate teaching the person with MND and their partner non-verbal communication techniques to continue their relationship

9.4.4. Trajectory of illness Learning Recommendations

Aspects of terminal care

1. Appreciation of the effects on the cared for of terminal disabling diagnoses
2. To have knowledge about the dying and bereavement processes in the disability context
3. To understand the concept of post traumatic stress syndrome which may be presented by lay carers (or even people with MND following diagnosis) and to know how to seek further intervention of required

Concepts of change in terminal disability

1. Appreciation of the impact of change which people face with terminal disability
2. Learn strategies to support change holistically
3. To understand the need for MND families to search for periods of relative normality for temporary respite from the acute fear and suffering

Time management/prioritisation

1. Professionals to develop time management strategies to maximise their limited time with those who need it in the emotional dimension as well as practical interventions
2. Increase inter-professional time for co-ordinated client interactions

9.5. THE CONCEPTUAL MODEL OF LAY AND PROFESSIONAL CARING

This final section of the chapter first considers the differences in the identified dispositional stance of the three participant groups (Bourdieu 1980). Then the conceptual model is presented which draws on the evidence from the study.

Bourdieu (1980) offers a general theory of practice and attempts to transcend the opposition between objectivism and subjectivism. Seedhouse (1991) is reported to state that care contains two languages; the technical and the non-technical. Bourdieu attempts to reconcile these two languages and 'to transform them into a dialectical relationship' (Harker et al 1990:1) which is consistent with the united practico-philosophical dimensions in this study.

It is not the intention to present a critical analysis of Bourdieu's work but to use the 'conceptual apparatus for the study of practical life [whilst emphasising] that these concepts are proposed as flexible' (Harker et al 1990:3). Bourdieu agreed with Heidegger that understanding the person cannot occur in isolation from the person's world. This mutuality of understanding, the person and the person's world transcends the singular significance of either when not seen in relation. Indeed Bourdieu's (1980) theory of practice is rooted in internalising the external and externalising the internal. By considering the person and his or her situation, the strategy exists to learn and understand from the practice of a person or group how these two influences affect their development. It can be aligned to Heidegger's 'throwness' experience and how one attempts to make sense one's situation through dispositional adaptation. Applied to the context of this study, it means that it can help explain what has been learnt about values and practice .

There is clear evidence that a change in circumstances, that is developing MND or having to care for someone with MND, demands learning and an adaptation of self. In pursuit of becoming we can recognise it's congruence to learning, as in becoming we are learning. To interpret the person in the person's contextual world, the values underpinning being and becoming in care need to be clear. These have been presented in the previous three chapters, with the ontological evidence illuminating a contextual epistemology of care. This knowledge has been transposed into learning recommendations with a view to influence educational programmes to develop and improve future practice. However, to further consider the stances of the three participant groups, to unravel the values of their internal and external worlds, the concepts of habitus, field and capital (Bourdieu 1980) are helpful tools. They can shed light on the dispositional aspects of the three participant groups.

Habitus relates to the internal and external manifestation of person-hood. The connection with Heidegger's concept of embodiment and dispositions of being was that it offered Bourdieu a way to 'analyse the relation between individual practice and the world' (Harker et al 1990:34). The title 'Habitus' was adopted by Bourdieu from ideas of Aquinas and Panofsky as he 'wanted to show that the individual existed not just as an individual but as a social product and that a generative principle was at work' (Bourdieu 1985 cited in Harker et al 1990:35).

Bourdieu suggests that habitus is 'a system of durable, transposable dispositions which function as the generative basis of structured, objectively unified practice' (Bourdieu 1979:vii as cited in Harker et al 1990:10).

Disposition being developed from both objective structures and personal history and therefore with adaptive potential. The three participant groups represent three different 'habitus' due to their different interactions with the world. This perspective contributes to an understanding of their three different caring values and ways of becoming in MND.

Adaptive 'habitus'

MND *disposition of being vulnerable and leaving the world*
LC *disposition of hard worker and selfless through love*
PC *disposition of separate to illness but functionally confident*

Field is an area of struggle and Bourdieu describes how society is a system of fields with each field having its own structure and field of forces. These are set within a larger field with its own field of forces, structures etc (Harker et al 1990). Fields are defined by a system of objective relations of power. Bourdieu talks about the intellectual field but applied to this study, field is the world of caring. The objective structures of the habitus are 'fields'. These connect the person to the social world.

The habitus of professional carers is influenced by the field of professional care and mixed with their personal histories. The field of professional care is 'normal' to them and it is their chosen niche in society; a professional language and way of being is evident in their field with sub-cultures amongst the various specialities. Patients and lay carers have not chosen the field of professional care, or been exposed to its cultural priorities. Once they enter it through virtue of MND, they have different responses requiring adaptation to their new 'habitus'.

Three struggles in the 'field' of care

MND *struggling to remain a person whilst being cared for*
LC *suffering selves whilst caring for another*
PC *professionally ready but constrained by external factors*

Capital exists within a field. It is a concentration of power linked to status. There are people who have a lot of capital and those who do not. Bourdieu illustrates capital in the field of intellectual life as authority and prestige. Symbolic capital is recognised as legitimate: to be seen as a strong intellectual is to be accepted as legitimate and sometimes as a legitimate authority. Bourdieu understands capital to carry power, represent 'common-sense' and create an official version of intellectual life.

However, capital and its use is open to dispute. Professionals may have an unequal distribution of capital in their field of professional care, where most power is rooted in the medical cure functions. Patients and lay carers have the least.

Capital - status and power

MND	*symbolic dependence/ culturally a burden*
LC	*symbolic dependence/culturally a hero*
PC	*symbolic legitimacy/culturally educated as the legitimate 'carer'*

Applied to the field of care, Bourdieu's model suggests the professional carer would hold the legitimate power to care for others. The ill person would have the right to be cared for but be viewed as a burden. The lay carer is in a more ambiguous position. Although capital in the field of caring traditionally lies with professional carers, more recently this is seen to be shifting to care managers and towards promoting the rights and privileges of clients. The capital of lay carers however is unclear and therefore weaker. Value given to capital is related to the social and cultural characteristics of the habitus. In summary, field, habitus and capital determine the style of practice, as fields change so does habitus. Bourdieu's theory of social practice is summarised as:

(Habitus x Capital) + Field = Practice

However, Harker et al (1990:7) reminds us of Bourdieu's warning that the theory's use is 'to provide an explanatory device for exposition, and does not in any way offer a universal solution for social action'. His is a method, a general manner of thinking, which demands the need to study each situation in its own context. Using Bourdieu's formula, and the findings from the three participant groups, practice or dispositions in care can be plotted (table 27).

Table 27. **Bourdieu's applied formula for practice in care**

MND practice of person in extremis = *(being vulnerable and leaving the world x culturally a burden) + struggling to remain a person*

LC practice of person adapting = *(hard worker and selfless x culturally a hero) + suffering selves*

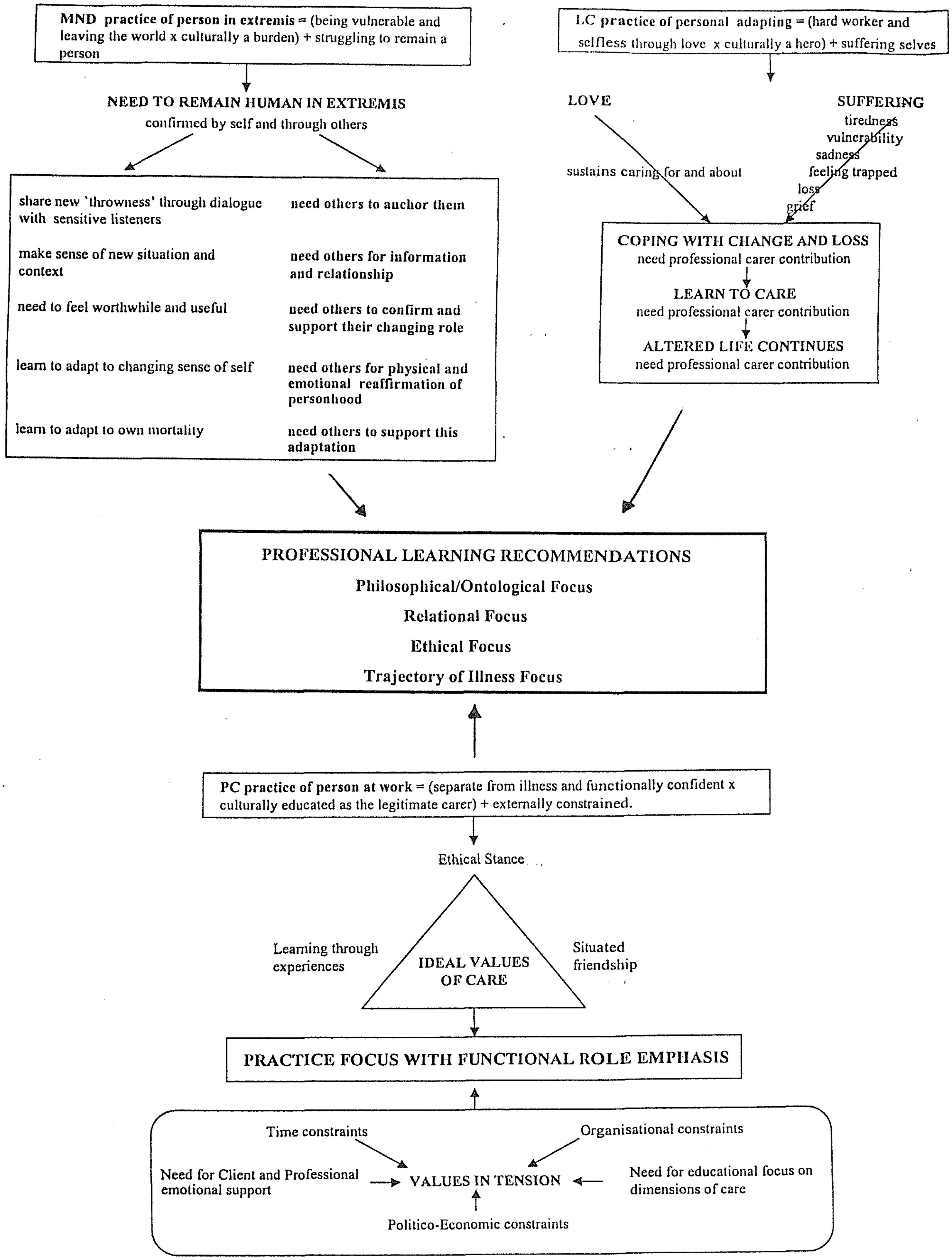
PC practice of person at work = (*separate from illness and functionally confident x culturally educated as the legitimate 'carer') + externally constrained*

This explanatory process offers insight into their different dispositional stances. The outcome offers a sense of need to bring about a fundamental dispositional shift on behalf of the professionals to effectively gain alignment with their lay clients and reduce the gaps in care delivery. Professionals need re-entry and sensitising to the lay world to appreciate the existential world of their clients. The research study offered me this opportunity and has broadened my horizon of understanding in care, promoted an adaptation to my habitus and led me back into the existential world of care. It has not dimmed the need for functional interventions but heightened my awareness of the need for thoughtful engagement coupled with action.

In the wider sense, if 'modernisation' is the current political route and this means that services are designed to meet the needs of those they serve (Milburn 1999), then this professional dispositional shift is needed. The professional learning recommendations could be seen as a beginning by mapping values from the care world to steer professional disposition, education and enhanced care delivery. Although the professional carer learning recommendations offer a vehicle for uniting these three worlds, it can be argued these alone are not enough. They may serve to re-focus the neglected human aspects of care delivery and open up horizons in the professional world. What is also needed is a dispositional shift in the organisational, political and professional values underpinning the current practice of care.

The lay and professional model of care (figure 15) reflects the current reality identified in this study. The professional learning recommendations signalling the beginning for a dispositional shift to greater alignment with lay participants.

Figure 15. Model of Lay and Professional care



9.6. SUMMARY OF CHAPTER

The gaps and matches in care delivery and receipt have been mapped out in this chapter. Four areas of professional learning recommendations have been identified which offer an educational approach for addressing the identified imbalance in professional care values. Bourdieu's theory of practice illuminates dispositional and situational differences governing caring values and practices. The conceptual model has been constructed drawing on all these elements.

CHAPTER 10: CONCLUSIONS

10.1. INTRODUCTION

Applying a phenomenological hermeneutic approach to this study has released and recorded voices of people immersed in the experience of care in MND. Three distinct stances and care values have been identified with most alignment between the two lay participant groups and most divergence between the lay and professional participants. The need for the delivery of holistic care is confirmed but its neglect is clear.

Dispositional and situational effects can be held to partially account for these similarities and differences as reflected through Boudieu's (1980) explanatory triad of habitus, field and capital. The conclusion signposts two opposing value bases; the functional or mechanistic view and the holistic or hermeneutic view. There appears a need for a dispositional shift within the professional carer community to reduce this divergence and to support the value base underpinning the practice of holistic care. The rebalance of professional curricula can be one strategy to support this aim through reducing the prioritisation of the practical functional 'hard' knowledge over the philosophical 'soft' values for practice. For further success, the underlying value base of care practices need to be broadened within the wider community.

It may appear that the professional learning recommendations set impossible standards for professional carers to reach in isolation. Extrinsic support is necessary to meet these recommendations/delivery requirements. Their realisation requires support from the wider community. This involves harnessing the identified external powers (organisational, political and educational) in support of transforming values underpinning professional practice as well as unlocking the potential of lay people involved in care.

However, we can turn to education as a key component for both approaches. Holistic caring values need to be owned by all who are directly involved. However, in this pursuit there is the need for someone/group to be responsible for its guardianship and promotion. How else can holistic care standards be established? How else can caring practices be protected and monitored and care delivery and receipt be developed to a desired level of delivery? Lay people appear to have an holistic value base established but do not have sufficient 'capital' to protect them. Professionals have the 'capital' but not the value base.

If professionals adopted and promoted holistic/hermeneutic values alongside their more mechanistic stance, then they could take the lead to share and devolve these caring values and skills to the wider community.

These two value structures, the mechanistic value base and the hermeneutic value base, currently appear in opposition. It can be argued that this distinction is not solely related to professionals and clients. Indeed there may be many clients who view professionals as biomedical mechanics (Toon 1994) as well as professionals who regard themselves as predominantly focused on interpretive aspects. It is gaining a sense of balance amongst all professionals that this study advocates, so both value systems can be mutually respected and harnessed for the delivery and receipt of care. In a terminal neuro-disability such as MND, the emphasis appears to lie in needing the holistic/hermeneutic stance but this has been revealed within the context of an overall satisfaction with the functional interventions.

In pursuit of setting an agenda to achieve this balance, the first section of this chapter returns to the evidence to consider implications of the professional carer learning recommendations. However, it must be clarified that this research is not a feasibility study for the implementation of the learning recommendations. That aim requires a project of its own. The second section summarises the outcomes and achievements of the study. This is followed by a critique of the study in the third section. The final section identifies implications arising from the study in terms of further research in the area of care.

10.2. IMPLICATIONS OF THE PROFESSIONAL CARER LEARNING RECOMMENDATIONS

The learning recommendations focus on the perceived gaps in professional care education. These are grounded in the need to redress the imbalance of care towards a more person-existential focus having discovered a pre-dominant physical functionalist approach to 'care'. Changes in curricula towards realising these recommendations would ideally first need to address alternative priorities in the organisational, social and professional stance to care, as the recommended content changes would need positive selection by the sponsors of education to signal their acceptance. Second, there would be the need to gain the support and contribution of the wider community, which also has a responsibility for values underpinning care delivery.

Third there is a requirement for the maintenance, protection and guardianship of these values by someone, or a group, who could accept this responsibility.

The assumption so far has been that redressing the imbalance in the professional value base is necessary for all professionals. However, a moment of exploration is required if this assumption is false. If the current functionalist outcome/mechanistic approach to professional education and training is to remain constant, rather than change the value base and develop educational strategies, there is an alternative option. That is to establish a new care professional who is educated and trained to meet the emotional and psychological needs of people. Their functional contribution would 'fit' the current model of professional care intervention with the specific remit to 'plug the gaps' left by the current professional carers. This new role would reduce the need for all care professionals to aspire to holistic care. 'Care' professionals could be renamed cure and functional interventionists. They could focus their practice, research, evidence and knowledge on their functional focus for enhanced effective interventions. Patients and lay carers could be informed of this shift to accommodate expectations. This 'new care professional' would follow an educational curriculum designed to meet the humanistic-existential needs of clients and their lay carers and only be concerned with this focus to the detriment of any other 'functionalist' intervention.

This approach would remove the need for promoting unification between the practical and philosophical aspects of care for all 'care' professionals. The current dominant professional habitus of being separate from the illness experience could be supported, the practical focus of being at work in a functional field could be supported with an enhanced capital located within society's valuation of the expertise of 'hard' knowledge. However, the unification desired between the aspects of 'doing' and the 'being' would be irrevocably lost through this approach.

If this alternative appears unsatisfactory, this leaves us to explore the other option, to address the imbalance of care values for all professionals. This would mean creating a dispositional shift to be realised in practice and raises the question of can this be achieved?

Reflecting on the dispositional stance of three participant groups at the point of diagnosis highlights the divergence to be overcome.

The MND group's first category of 'existential shock', is in parallel to the 'de-stabilisation' experienced by the lay carers. However, the professionals first consider their functional strengths which is a world away from the existential needs of the clients. The absence of ontological understanding, realisation of the effects of a MND diagnosis can create an incompatible way forward in the first instance. This in turn can affect the totality of the subsequent client-professional relationship. Selecting curriculum content to support the professional learning recommendations can then be seen as not merely 'plugging the perceived gaps' but moving towards the client-led value base, an holistic/hermeneutic sense of need balanced with functional intervention. This demands a dispositional shift. Professional carers need to move from being detached from the illness experience to understand it as well as being excellent in their functional intervention skills.

10.2.1. Selecting curriculum content

The professional learning recommendations are considered supportive of the desired dispositional shift. Achievements in improving philosophical/ontological understanding, relational knowledge and ethical dimensions would influence underpinning values and practice approaches coherent to implications identified in the disease trajectory. The first two groups are considered in relation to selection of curriculum content.

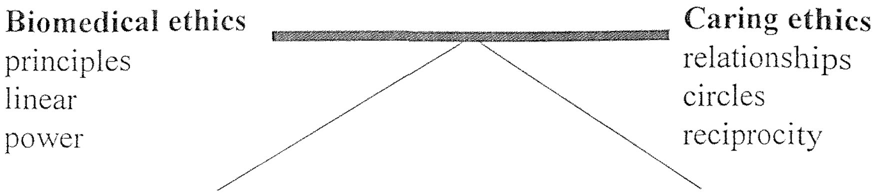
The philosophical/ontological explorations would include addressing questions of 'what it is to be human?', 'what is care, illness, vulnerability, compassion?'. These 'hermeneutic' values could be studied alongside the 'mechanistic' value base. The philosophical explorations could draw on the work of protagonists as presented in chapter 2, including the Greeks, Aquinas, Heidegger, Buber and Mayerhoff. Their ideas could be applied to the reality of practice supported by textual lived experiences through client and professional narratives, appropriate autobiographies and research together with professionals' own experiential learning in a range of practice settings. Holism as a practice outcome could be promoted. A multi-disciplinary context would be appropriate for this exploration and learning. The promotion and practice of the therapeutic use of self could be critically explored to enhance appreciation of the effects of the self in human interactions and functional interventions. A reflective stance would be most supportive to draw the theory and practice elements together as well as supporting the 'holistic' development of the care professionals.

The inclusion of a broader ethical horizon in care would draw on the work of Kohlberg (1986), Gilligan (1982) and Noddings (1984), (see chapter 2. Section 2.5.4). Kohlberg's model of moral development is linked to the biomedical ethical principles. It is a linear model of progress and development supportive of justice based decision-making. Gilligan (1982) challenged this as the only route. She found different social learning experiences led to different ways of personal development and values. Males learn to value separation, self-esteem, skills and knowledge, abstract rule-governed thinking. Females value relation, connectedness, responsibility to others, understanding with an emphasis on experience. These two contrasting approaches led her to conclude there are 'different paths of development….the different ways in which the experiences of separation and connection are aligned with the voice of the self' (Gilligan 1982:39). Although her work progressed to the development of a caring ethics, this work is pivotal for also addressing aspects of the relational and philosophical/ontological recommendations.

Gilligan's findings clearly propose that women's learning is different from men's, there is this 'different voice'. This different voice focuses on relational, ontological and ethical aspects of being; the main gaps identified in this study in professional care delivery.

Indeed her data suggested that 'rather than linear development, it may be more appropriate to see women as engaged in cyclical confrontation: moral values stressing altruism and connection' (Davies 1995:26). Suspending the gender bias but applying these two approaches to the evidence in this study, it can be argued that appreciation of both ethical stances are imperative. The cared for and lay carers need decisions, judgements and positive interventions but they also need a sense of altruism and connection. Professionals were found to be well practised in the biomedical ethical rules but with deficits in caring ethical practices. Professionals need education in both; the linear for informing practical action from an ethical stance and the cyclical for supporting the ethical, relational and ontological practice. Professionals need education in both ways of thinking to inform their action and ways of being (figure 16). Currently, the caring mode appears neglected.

Figure 16. Re-balancing the ethical focus for professional education



Noddings (1984) goes so far as to suggest caring needs to be the primary aim of education. This statement has resonance with comments from Jarvis (1997) that learning itself is amoral but what is selected to be learned is a power issue with moral intentions. This selection process needs re-balancing if caring is to become the primary aim of education. The external factors would need to accept this deficit and act accordingly. At the delivery end, the educator would need to practice as one-caring, whether that be towards the human audience or towards the 'craft' or knowledge that is being discussed. In this argument, if caring were the dominant way of being and way of action, it pervades existence and unites the practico- philosophical division that is so often encountered. This premise puts a responsibility for the instigator to act as the one-caring and offer a model of delivery to this effect for students.

In summary, Nodding's starting point to influence curriculum development and educational organisation would be 'identifying the maintenance and enhancement of the ethical ideal as the primary function of any educational community' (Noddings 1984:182). This would be supported through exposure to philosophical questions, writings and debates. This deliberate and conscious action would need to be supported by the organisational, political and professional authorities to initiate this change. It would challenge professional educational institutions to promote a combined approach towards biomedical and 'caring' values for underpinning practice. In collaboration with service providers this stance could influence the organisational and managerial cultures towards a more humanistic value based focus. The masculine/traditional organisational structures of hierarchy and power and practice could be re-balanced by maternal or female orientated 'circles and cycles and chains' of practice.

10.2.2. The contribution of the wider community

There is the need to harness the contribution of the wider community which has a responsibility in care. Under this theme of co-operation and commitment, a particular area of concern for the cared for and lay carers is the need for inter-professional co-operation.

This extends to voluntary agencies of lay people which suggests a positive inter-active contribution from the wider community.

An example of the effectiveness of multi-agency co-operation is reported by the MNDA (1999). One voluntary worker (MNDA regional care adviser) and a team of four professionals (neurology nurse, occupational therapist, dietician, physiotherapist) collaborated in 1996 to offer a therapist's clinic to people with MND. This clinic was held as a model of good practice through winning the 1999 Michelin Excellence Award in association with the National Society for Quality through Teamwork (MNDA 1999).

The new Primary Care Groups are another example of promoting more effective inter-professional co-operation. They are based on a commissioning model whereby what is needed to meet existing and future heath care needs is planned with local services under the control of local practitioners (community nursing services, social services, local GP's and a lay representative). Absence of the paramedical staff is an omission here which should be addressed. In terms of MND provision, as the numbers of people with MND are relatively small, meeting local needs might lead to their exclusion, so organisational boundaries would need to be porous for certain client groups.

Developments for further inter-professional co-operation in care are currently supported by government, professional groups and voluntary agencies. The World Health Organisation published its report on multi-professional education of health personnel in primary care contexts, 'Learning together to work together for health' (WHO 1988). However, the disposition shift advocated would need to be part of the learning content. The WHO's report links the proximity of practice to educational provision which is defined as,

> 'where health related occupations with different educational backgrounds learn together during certain periods of their education, with interaction as an important goal, to collaborate in providing… health related services' (WHO 1988, 6-7).

Although social services are neglected in this report, (the WHO is health focused) it does not mean provision cannot be made in certain areas of care curricula.

A key feature that seems to be missing was highlighted by the WHO which states that not only are individual disciplines important but central to their combined effective working are robust processes 'through which the team as a whole is led and supervised and approaches problems' (WHO 1988:8). The notion of leadership requires adaptability, a sense of identity, the ability to discover and interpret the working environment. So who would be the most effective leaders to promote caring in a multi-agency approach? Should lay people take on this role or professional people? Who should be the guardians and protectors of care practices?

10.2.3. Protection and guardianship of care

This third section offers a suggestion as to who should take on this responsibility to maintain the protection and guardianship of caring values. The need for such a role is paramount as current health care practices are increasingly being criticised for not offering clients the care they expect (Phillips 1999). Nurses are the traditional guardians of care who seem to have abrogated their responsibilities but still live within it's spirit. The district nurse in this study confirms that spirit through sharing,

'I'm just conscious that you need to look at the whole person and not just the physical side of things………. if you don't have your ideals where do you start' (PC3).

Her values were not limited to functional areas but focused on the whole person. This admission has placed nursing in a state of tension, seemingly without a specific function and with accusations that nursing has lost its way in a world of measurable outcomes. Its continuing strength however lies in its focus on the person.

This suggests the discipline of nursing is the natural leader to rekindle caring values, to lead its promotion and guardianship. The historical legacy of nursing is also supportive to this way forward. Nursing has long laid claims to caring as being the essence of nursing (Benner & Wrubel 1989, Bishop & Scuder 1991, Roach 1982, Leininger 1980). This claim reflects the vocational, oral history of nursing which traditionally promoted caring virtues such as service, compassion, commitment and dedication. Indeed, American nurse educationalists promote care as being at the heart of their curriculum and highlight the importance of the caring imperative in nurse education (Leininger and Watson 1990).

Nursing should reflect on its heritage, its espoused values for practice, theoretical and experiential knowledge base and educational potential to actualise and protect its underpinning core values. It should accept responsibility for the guardianship of care and not abrogate it again under the influence of mechanistic values. A useful structure to support this guardianship is offered by Roach (1982). Her framework, illustrated in table 28, links closely to the professional learning recommendations..

Table 28. Comparison of Roach's framework and the professional learning recommendations

Roach (1982)	**Learning Recommendations**
Conscience -	Ethical
Commitment-	Relational
Competence-	Functional
Compassion-	Philosophical/Ontological
Confidence-	Combination of above and Trajectory of illness
with the important addition of a sixth C - Co-operation.	
Co-operation	Relational in all dimensions of care delivery and receipt

Part of the responsibility of guardianship should lie with unlocking the potential of lay carers and the cared for. The lay participants in this study clarified their ability to learn to care and their receipt of care from the voluntary organisation who were praised for their practico-philosophical interventions. Co-operation therefore needs its own standard.

Caring has been presented within a triangle of participants. All sides of the triangle should therefore have a sense of responsibility for its standard of delivery.

10.3. STUDY OUTCOMES AND ACHIEVEMENTS

The major outcomes and achievements of this study can be considered in five areas:

- Care theory
- Care practice
- Care education
- Management
- Research approaches

Contribution to care theory

evidence base of experiences and values of care
three perspectives in one study

The evidence presented contributes to an understanding of the experiences and values of care in the world of motor neurone disease. It is particularly significant that the study listened to the voices of three groups in caring. Evidence from one perspective can be limiting. The differences in lay and professional values are highlighted with two opposing value bases in operation.

Being in care is illustrated through the three participant models displaying the interconnected nature of the emergent categories. The conceptual models capture the central values of the three groups. The lay and professional model captures the situatedness of care and the associated recommendations for redressing the imbalance in care for practice delivery. The debate on the need for professional dispositional shift focuses the strengths and limitations of current care values underpinning professional practice.

Contribution to practice

importance of values in practice
exposure to different horizons in care
co-operation in practice

Practice is the end point of values. This study has identified common ideals of care values related to being human, which appear in tension in the professional domain. Listening to existential realities uncovers these essential values and offers the opportunity to learn from them in an attempt to redress the imbalance. Understanding similarities and differences can contribute to a change in horizon and practice.

The evidence and models offer insight to the worlds of the cared or, lay carers and professionals facilitating this insight for each other. It offers understanding why differences are present in caring values and appreciation that although individuals are motivated to care how organisational, economic and political constraints can influence their practice.

The professional learning recommendations challenges the need for re-balancing underpinning values and advocate co-operation between all caring partners. Inherent in co-operation is the need for supportive strategies for all involved in care through reflection and communication.

Contribution to education

value impact on practice
extension of horizons
clarification of habitus
individual group caring models
professional care learning recommendations
identification of deficits for educational action

The evidence gained from the ontological investigation offers knowledge for dissemination. The impact of values on practice promotes evaluation of current educational provision to care professionals. Suggestions have been made for nursing professionals to lead on the guardianship of care and to extend care education to the wider community for greater participation and ownership of care practices.

The distinctions in habitus between the three groups is clear and is offered as evidence for the need to extend horizons of the participant groups. Dispositional change is supported by the professional learning recommendations to improve their value alignment with lay participants. The individual models clarify their respective prioritisation of care values and current temporal trajectories.

These professional learning recommendations are targeted on the professional educational curricula but also serve to offer an evidence-based for underpinning general care education. Functional specialities of care appear well served by the care professionals but the imbalance and deficits lies in the four groups identified; philosophical/ontological, relational, ethical and trajectory of illness. Suggestions are made for redressing these deficits but these would need further research to elucidate their effectiveness.

Contribution to management/organisational aspects

raising awareness of consumer perceptions of care delivery
awareness of lack of fast track arrangements
need for hospice interventions
need to establish a resource equipment store
greater co-operation between health and social care finances
promote greater co-operation between care professionals

This study clearly captures the 'consumer' views of care delivery in MND. Practical information should be useful for managers and organisational planners responsible for neuro-disability services. The satisfaction with functional interventions offers a positive message but the negative aspects are located in the brevity of time professionals have for delivering care which is linked to a shortage of personnel. Inherent in this time restriction there is the lack of emotional care for patients. Additional points worthy of note for managers and organisational planners which should be considered are,

- need for hospice provision for MND patients,
- need for immediate availability equipment stores,
- need for specific inter-professional teams
- need for designated co-ordinators of care for patients with MND
- need for immediate social care support for people who have rapidly developing terminal disabilities

Contribution to research approaches

researching at the edge of life and communication abilities
combining application of hermeneutics with phenomenology
developing an analytical tool
rigour of decision trail
clarity of outcomes

A particular feature of this research was working at the edge of life and communication abilities. Engaging with the cared for and the lay carers in particular was a challenging process as a research activity. Communicating about their extreme situations required sensitivity, emotional labour and self-awareness whilst establishing a relationship of trust to encourage them to offer their experiences.

Strategies for enhancing effective communication in a research situation with dysphasic people have been described in chapter 4. This process demanded the researcher draw on personal resources whilst being aware of ethical considerations to protect the participants. Influences of the research on the participants and the researcher were captured through the researcher's reflective diary entries (examples in chapter 5, appendix 6) and in gaining responses of the influences of the conversations on the participants. Leaving the field of relationships was also a challenging aspect of this research which enhanced the sensitivity of the researcher to the worlds and experiences of the participants. The research enhanced the understanding and horizon of the researcher to living in the world of MND. This gave more insight into the challenges before all three groups of participants.

The study exposes the value of the application of phenomenology and hermeneutics. It develops and uses an analytical tool for handling the evidence which could be repeated. The rigorous decision trail should offer researchers the opportunity to replicate or use the tool themselves if appropriate. Despite these contributions, it is acknowledged there are also weaknesses which are now addressed.

10.4. LIMITATIONS OF THE STUDY

Any study has its limitations and this section intends to highlight its main limiting features; application of phenomenology and hermeneutics, a new analytical tool, sample attrition and availability, implementation of recommendations and application of qualitative rules of rigour.

Inductive research offers no aid in prediction or control of variables. If a reader was trying to identify measurable outcomes then this study does not contribute to that aim. However it does contribute to an understanding of the issues, concerns and limitations which may help

'anticipate future events for a person or family and aid in the understanding of the significance the person or family gives them' (Plager 1994:80).

Application of phenomenology and hermeneutics signifies an interpretative turn rather than utilisation of an objective approach. The process of interpretation could be challenged. This study has offered a decision trail to promote the robustness of the analysis method but as the interpretative analysis process was developed for the study, there is no previous work which can support its robustness.

Not all people are able or willing to be involved in this sort of in-depth study so it could be argued that a certain typology of person is attracted which would influence evidence and hence outcomes. All the MND participants knew they were at the end of their lives which could be viewed as skewing their contribution from this perspective rather than care.

Securing a stable sample was not always possible as experienced when one MND participant died before the 2nd conversation and one MND participant refused the second interview as it was too distressing. These limitations meant that instead of a full sample of six people with MND, only 4 MND participants were available for a second interview. One professional carer left her area of work so only five second interviews were possible in this sample group. However, in the real world of research with people in extreme situations such limitations have to be endured.

Securing participant consensus on all the first level themes was not possible. However, the remaining participants offered limited correction which was supportive of the researcher's interpretations. The two research supervisors were involved as an analytical panel to strengthen judgement for the robustness of the analytical decisions made by the researcher.

The MND and lay carer sample offered a sense of homogeneity by the nature of their experience with MND whereas the professional carer sample was diverse in terms of their varied disciplines which could be seen as a limitation. However, as explained in chapter 4 this decision was taken for a purpose, that of emulating the MND experience of engaging with many care disciplines Although no individual in any group was asked to affirm each others evidence directly, through offering their own contributions a level of saturation was gained. In pursuing some cross-validation of evidence for the individual disciplines, there was a lack of additional professionals who could be consulted on the issues, this emerged as few additional professionals could be identified as being involved in caring for people with MND. Three additional hospital consultants were interviewed which raised no contrary evidence. However, the situation served to highlight a predicament of research when a sample is unavailable despite searching attempts.

The professional learning recommendations are presented as an outcome of the research and are not intended to attract a critique in relation to the feasibility of their actualisation. Although suggestions are made in relation to curriculum development, a further study would be desired to consider an implementation strategy and effects of the recommendations.

Throughout this thesis, there is an emphasis on clarifying the decision trail of the researcher. The notion of a decision trail is an issue in establishing rigour for this research. Koch (1994:976) argues that the 'trustworthiness (rigour) of a study may be established if the reader is able to audit the events, influences and actions of the researcher'. Readers may not share the same interpretation but they should be able to follow how the researcher reached her conclusions. It has not been possible to include all aspects of all the decisions taken in this study, which can be viewed as a limitation, even though examples are included to support its critical reading.

Guba and Lincoln (1989) recognised how the use of three criteria; credibility, transferability and dependability can support academic rigour in qualitative studies.

These have been discussed with strategies identified to support their actualisation. Tripp-Reimer & Cohen (1987) have criticised interpretative work as being biased towards the researcher's knowledge and experience and for not being true to the participants' lived experiences. There is a risk of influence in all research endeavours. This study has endeavoured to illustrate how it has remained close to the evidence, to offer a clear decision trail to uncover prejudices for scrutiny. In addition, the researcher explains her own caring prejudices and background to uncover prejudices. This endeavour for researcher credibility is to permit the reader to appreciate the historical fore-structure of the interpreter. The participants and researcher supervisors also acted as cross-validation auditors to this effect.

A question to be asked is 'Can the findings be generalisable to other situations apart from motor neurone disease?' The claim to this stance would be in the negative which might be seen as a limitation. However, readers are encouraged to make their own judgements. Transferability refers to evaluating whether the findings can 'fit' into 'contexts outside the study situation and when its audience views its findings as meaningful and applicable to their own experiences' (Sandelowski 1986). Projection of this notion suggests that other terminal disease processes cause immobility, speech difficulties, certainty of premature death but within an uncertain time frame and require multi-disciplinary involvement. Conditions such as cerebro-vascular accidents, brain stem infarctions and certain cancers have similarities to MND. Possibilities for transferability would be linked to patients and carers in these areas. The literature in chapter 2 illustrating the experiences of people with these conditions offers a sense of resonance to the findings in this study. The learning recommendations are also not being produced with claims of transferability. Although if one is involved in a practice area where philosophical aspects of care appear diminished then the learning recommendations may well be a useful discussion focus.

Sandelowski (1986) considers a study can be judged dependable if another researcher can clearly follow the decision trail.

Koch (1994:977) adds that 'leaving a decision trail entails discussing explicitly decisions taken about the theoretical, methodological and analytic choices throughout the study'.

Attempts have been made to offer a clear decision trail, restricted only by word limits and space.

10.5. IMPLICATIONS FOR FURTHER RESEARCH

This final section considers implications for further research. This is an important consideration as one study often serves to raise further questions.

MND is specialised and focused. Further research into caring values with participants with other disease foci and different disease time trajectories is needed. Are there different care values in different disease categories? Are there different care values when people are in terminal situations as opposed to cure situations? What would be the experiences and values of care in long-term non-extreme disease contexts?, with short non-extreme term diseases? Would a client group prefer practical intervention alone in short-term care situations or is emotional care always a pre-requisite for perceived good practice?

The lay carers in this study were identified as the spouse of the cared for. However, social carers are a very important group of carers in the community and their values of care are influential to care delivery and receipt. Research into their values of care would therefore offer important knowledge for the development of care delivery and may further support their programmes of preparation for their practice.

This study presented professional carer learning recommendations. However, this is not intended to limit or reduce the significance of learning by the lay carer and cared for which need examining in their own right. What benefits might be gained from further consideration of the cared for learning needs? Would programmes with supportive learning outcomes be desired by clients and lay carers who currently receive their instruction on a need to know basis rather than from a menu of opportunities?

The geographical location of this study was limited to the South Coast of England. Further research could investigate caring values in a diversity of geographical locations, cultures and socio-economic groups to appreciate possible variations. There is no comparative benchmark for appreciating how the organisation of care in other health authorities is offered, for instance the provision of hospice care. A mapping of care provision across the country would serve a useful function. It would permit health authorities to learn from each other the preferred modes of organisation as well the least preferred modes for client care.

LIST OF APPENDICES

APPENDIX 1

POETRY BY GEORGE MACBETH (1991)

Extract from **'Laughter in Hell'**

I'm a baby
Growing backwards. Every day
A little less. Can't walk
So many yards. Harder to pour the tea.
Phlegm in the throat. I have a bath
With qualms. Approach bumpy ground
Leaning on someone's arm. Type
With a lot of difficulty.

APPENDIX 2

POETRY BY ANNE FISHER (UNDATED)

Extract from **'Voices'**

For every word I am able to say
there are a hundred left unsaid
because I lack the energy
to express the word
or by the time I have written them
the conversation has moved on.
And even when I have said something and been
understood,
the emotion is missing and the essence lost.
And so you miss knowing
part of me.

APPENDIX 3

GUIDED CONVERSATION SCHEDULE FOR MND PARTICIPANTS

FIRST CONVERSATION GUIDE - MND

1.What is it like to have MND?

Cues

-How has MND affected the practicalities of your daily life?
-What emotional changes has having MND brought about?
-What would be your goals for a typical day?
-How are other people assisting you?
-How would you describe the sort of caring environment you have at home?
-Have there been any significant turning points in the disease pattern?
-How has society reacted to you since having MND?
-What do you feel about the disease?

2. Are your thoughts concerning caring changed as a result of experiencing caring?

Cues

-What do you feel about being cared for?
-What are your main practical concerns about being cared for?
-What are your emotional concerns about being cared for?
-What are the consequences of these for you and your family?
-What do you anticipate in the future?

SECOND GUIDED CONVERSATION - MND

1. Are these interpretations (themes) representing your experiences?

Cues
-this is what I have learnt from you is it correct to your experience?
-this is what I understand you were meaning from your experience, is this so?

2. Had you learnt anything/been affected by our first conversation?

3. Have there been any changes in being cared for since our last meeting/anything you would like to add?

APPENDIX 4

GUIDED CONVERSATION SCHEDULE FOR LAY CARER PARTICIPANTS

FIRST CONVERSATION GUIDE - LAY CARERS

1.What is it like to care for a person with MND?

Cues

-What do you feel about caring for (people) with MND?
-How has this impacted on your daily life?
-How do you practically care for .....? Please give examples
-How do you emotionally care for....? Please give examples
-What sort of caring environment do you have at home?
-What are the goals of a typical day?
-What changes have you noticed in...Physically/emotionally?
-What do you feel about the disease?
-How are other people assisting you?
-How does society react to you caring for...?

2.Are your thoughts concerning caring changed as a result of experiencing this caring you are involved in?

Cues

-Can you say something about how you feel about caring for...?
-What sort of changes, if any, have you noticed in yourself through caring?
-What are your main concerns in caring for...?
-What constraints has caring out on you?

SECOND CONVERSATION GUIDE - LAY CARERS

1. Are these (my) interpretations of themes with you examples representing your experiences, Are they familiar to you?

2. Had you learnt anything from participating in the first interview?

3. Have there been any changes in caring since my last visit?/anything you would like to add?

APPENDIX 5

GUIDED CONVERSATION SCHEDULE FOR PROFESSIONAL CARER PARTICIPANTS

FIRST CONVERSATION GUIDE - PROFESSIONAL CARERS

1.How do you help in the lives of people with MND?

Cues

-What do you feel about caring for people with MND?
-What are your goals for a typical visit?
-What do you feel about the disease?
-What sort of approach do you take with your patients?
-What sort of qualities do you think you bring to caring for people with MND?
-How do you liaise with other carers?
-How could your professional help people with MND more?

2.Are your thoughts concerning caring changed as a result of experiencing caring for people with MND?

Cues

-Has our understanding of caring changed through experience of people with MND?
-Do you recognise any changes/affects in yourself by caring for people with MND?
-Have there been any personal consequences of caring for people with MND?

SECOND CONVERSATION GUIDE- PROFESSIONAL CARERS

1. Are these (my) interpretations of themes with your examples representing your experiences?

2. Had you learnt anything from participating in the first interview had it affected you at all?

3. Have there been any changes in caring for x since my last visit with you?/anything you would like to add?

APPENDIX 6

ANALYSIS TRAIL FOR LC THREE: REPORT OF FIRST GUIDED CONVERSATION

Introduction to LC Three

Mrs Jenny Three was a housewife in her late 30's. She was a slim small woman with a welcoming, happy disposition as well as seemingly, albeit falsely, to be somewhat disorganised. She was the mother of four children (aged 6-16) as well as the wife to Henry who had been a strong successful man prior to MMD, on whom she clearly doted. She was very much the housewife partner with no apparent personal ambitions for herself beyond supporting her husband and children. She was very committed to finding out all she could about MND and they both regularly attended MNDA meetings. I has seen them at such meetings but had never approached them for fear of coercing them into the study. The MNDA Voluntary Visitor had suggested the idea to them during one of her visits and they had agreed to meet with me.

The introductory meeting

Hectic was the word that first came into my mind on the introductory visit. Whilst waiting on the door step with the MNDA Voluntary Visitor after ringing the bell, Mrs Three emerged to open the door whilst eating a sandwich. As she tried to welcome us the radio was blaring and we had to pick our way through the hall into the kitchen where her husband (MND3) was seated in his wheelchair.

I felt rather an intruder into this domestic scene as both the MNDA Visitor and myself were sat down in the kitchen with them as they continued to finish their lunch. It seemed a very busy household and I felt uncomfortable that I was forcing a situation of further pressure on them by this visit. I was shocked by the state of her husband as he was a large framed man who had obviously lost a great deal of weight. He was having tremendous difficulty eating his lunch and everything seemed to be in slow motion from trying to chew his food to drinking his fluids through a straw from a beaker. He was still able to speak a little although it took some 'tuning in' to his speech. Jenny did not try to speak for him or through him but behaved as if this was a normal scene (as indeed it was for them) and invited me to talk to them both about the study.

After I had said my piece about the research study, Jenny seemed very enthusiastic to participate. She clearly indicated that it was very hard physically coping with him as she had to get him up in the morning, bath him, dress him take him to work and bring him home for lunch. This was all openly said in front of Henry but I was unsure about Henry's reaction. He also agreed to participate in the study but seemed much calmer although I put this down to his communication problems which hindered him from making spontaneous contributions. His speech was a laboured affair, he needed time and quiet when he offered comments. The calendar was taken down from the wall with all its entries and corrections and a date was fixed for the first meeting.

The first guided conversation

My first visit alone to this household was to have a conversation with both Jenny and Henry although separately. I arrived at the agreed time and again they were in the middle of their lunch although this time some of the children were around which made the household feel even more chaotic. There was washing over the kitchen floor, the washing machine was on and as I had walked through the hall I could see chaotic states in most of the rooms. It was a wet summer's day and as I was driving to the house I realised I was quite nervous and had still not lost my guilty notion of intrusion. When I saw the state of the house though I felt I should go into helping mode and assist Jenny. She appeared unperturbed by it all.

It was decided that my first conversation would be with Henry. Jenny had to move him from the kitchen into the living room and then transfer him from his wheelchair to his specialised armchair. One of his young daughters had to be asked to leave the living room to allow us to meet privately which she did reluctantly as she was watching a video. It was a challenging meeting as his speech was difficult although comprehensible and I was quite exhausted on its conclusion.

For my meeting with Jenny, we sat in the kitchen and had a cup of tea together. I was glad to speak with her second as the conversation was so much more fluid and easy in comparison to the attention to speech I had need with Henry.

Jenny told her story with fortitude, nervous laughter and pride in her achievements at being the main carer for her husband. Henry had obviously been the rock in the household for her as she reported he was a quiet, capable, loving figure who was the traditional man of the house whilst she was the wife and mother who was provided for financially by him although it was she who cared for the house and the family. This arrangement had worked well through their marriage and the arrival of their four children. Since Henry developed symptoms of weakness and received his diagnosis however, there had been a great shifting of roles. She had taken more responsibilities, experienced sadness from dreams which could no longer be realised and had her expected future taken away from her. She was now driving a large people mover vehicle to allow Henry to be transported in is wheelchair to and from work, she was increasingly becoming his voice and body organiser as his own physical powers diminished, she had endless disturbed nights as she was turning him over or helping him to the bathroom, she was striving to maintain a new normality as the old life was slipping through her fingers, uncontrollably.

An important feature in her story was how she never lessened her love or regard for Henry. She never found him less of a person through his physical deterioration indeed she talked of how he was still caring for her, he would try to help her with his care or ask her not to bathe him if he saw she was too tired. She would still defer many decisions to him even though she was becoming more able and confident but she knew how important it was for him to still feel an important part of the household.

After the diagnosis, they had both wanted to know all about MND to try to make sense of it. find answers to the many questions they had and see what they could do about it. They searched for meaning as to why it may have happened to Henry and information to prepare for the darkened future. She admitted that their reading hunger overtook their lives and the disease took precedence in the household over everything, even the children for a while.

In this situation though of endless physical labour and emotional torment she was adamant that other people did not feel sorry for her. She identified that caring in this context was about dependency and suffering, from all individuals concerned not just for the one with the disease. She detracted the need for sympathy but spoke of how she was recreating herself and was developing new but shifting normality's as her husband's symptoms worsened. She talked about reclaiming her life and the need to move on in the vein of being the lay carer to a loved one with a terminal illness but also with other family responsibilities. She had found health professionals supportive in that equipment and physical support was available which she accepted as their role but particularly valued time health professionals could talk with her and be tuned in to what Jenny was experiencing.

She talked a great deal about learning to care and problem solving skills she gained. She was always looking for a silver lining in that even though he still worked in the morning, he was home in the afternoons which meant they had more time together than when he had worked full time and indeed much overtime when he was well.

In terms of outside help she knew Henry was not keen on the idea as he wanted her to care for him although he agree when she was getting very tired. She equally did not want social carers as she felt pride in her achievements and gained personal reward for her efforts. Indeed the only outside care they requested was for a sitter at night but there were financial difficulties between the health and social departments and so this did not materialise. Henry died before bureaucracy supported them.

APPENDIX 6A

SECOND GUIDED CONVERSATION STORY FROM LC THREE

Summary of second conversation with Jenny

I returned to Jenny within a three month period during which time Henry's condition had deteriorated markedly and Jenny's pressure for coping had increased. Again I had arranged to meet with both of them on the same occasion although separately. On entering the house I could see that she was still pressed as the house was still in a state of upheaval and they had just finished lunch following returning from Henry's place of work. I met with Henry first and then spoke with Jenny in the kitchen. She agreed with the accuracy of the transcription and told me how she had 'quite enjoyed talking. I think it helps to talk things out' she even went so far as to state she had been looking forward to talking with me again. She found that talking allows the worry element to be shifted elsewhere for a while although she expressed that this made it better to talk to strangers rather than close friends and relatives as she would then worry that she had burdened them.

Throughout my conversation with her she seemed to have gained a deeper calm. It was as if she had developed even greater confidence in caring for her husband, which she confirmed, but also as if she was preparing herself for other things, letting him go, preparing for his absence through death. We started by talking through the first level themes I had identified and she agreed with my interpretations, for example she had talked about how she found certain situation in caring for Henry funny which I interpreted as a 'Humour as a coping strategy'. She agreed with this interpretation adding, 'I really do find things very funny and I laugh ever such a lot about silly little accidents and when things go wrong. It just happens, just better than crying, it just happens that I laugh'. I felt as if I had 'clicked' with this woman in terms of appreciating where she was located in the world of caring which had permitted me to identify, appreciate and interpret her experiences accurately. It was as if my horizon was able to encompass her experiences and permit me clear insight into the experiences she had talked about; our horizons were already on a level with each other.

The preparation for the next predicable stage of events did surprise me although I immediately accepted the importance of what she was doing. I was checking out with her the theme 'shifting roles' and how she seemed to be taking on more responsibilities in caring for Henry was he was becoming more dependent. She entirely agreed with this but began to inform me how she was changing again in that 'I feel now we're trying to get away from it a bit, well, obviously he cannot get away from it as much as I can but I'm trying'. In this she statement she was not indicating a reduction in her care or a removal from the seriousness of the situation but really about she was responding to seeing her husband decline so rapidly now, she added, 'I don't know whether it's like compassion, when you've seen enough terrible pictures you kind of switch yourself off' and this led her to further remark, ' you can't do anything about it and you've got the try and concentrate on your life more'. These statements were very interesting to me as Henry had previously said how he considered his family were 'mourning my death already' and it seemed he was right. It seems quite reasonable as well that she was preparing for the next stage, her life without him and quite emotional that he had recognised this and had accepted it. (In the thematic construction this findings was incorporated in to the LC category 'Preparing for loss'.

As the second conversation was drawing to a close I could feel that Jenny had enjoyed talking to me and even went so far as to say, 'I quite enjoy talking to you. Perhaps I'll ring you up one day'. Indeed three months later Henry died.

APPENDIX 7

ANALYSIS TRAIL FOR PC SEVEN: REPORT OF FIRST GUIDED CONVERSATION

Introduction to PC Seven

Mrs Ann Seven was a lively energetic woman in her late 30's. She worked part time as a community physiotherapist as she had a young family. She was articulate and appeared confident in her knowledge of caring for people with MND and was aware that in the identified professional caring team she was one of the community staff who had had the most experience with working with people with MND.

The first guided conversation

Ann was very welcoming to me on the first meeting at her house. She had just returned from work so was in uniform after a busy morning. She made us both a cup of tea and we moved from the kitchen to her dining room table where we sat for the recorded conversation.

She was very interested in the research as she felt that MND was on the increase as it was certainly reflected in her own practice. She clarified that when she was a hospital based physiotherapist, over 7-8 years she had perhaps only seen one case of MND. However, since working in the community she has been involved with at least 10 people with MND. This situation created quite 'big learning curve' as initially when she visited them, 'you haven't a clue what's going on, you have to read up a lot initially to find out what's happening'. Most reading material came from the Motor Neurone Disease Association but it was not just the functional needs that demanded attention as she was well aware.

She highlighted her recognition of the importance of the lay carer, recognising that maintaining a person in the community rests with the carer and family. She spoke of the dependency of people with MND which would require high levels of nursing staff in a hospital situation. This would create far more financial demand on the health service but clarified that when Jenny and Henry tried to secure night respite care it took too long to be agreed. In the realm of further support for people with MND she also learnt that apart from the available community team, people with MND were not treated in the same category as cancer patients. She stated 'the hospice will provide equipment for a cancer patient but they don't seem interested in MND' so it is 'very much down to whether the local (community) team are interested or not'. Her own learning had also been affected by her personal experiences of having children. The sense of vulnerability she recognised in her child she applied to her patients in that it brings sharper into focus that when thinking of Jenny and Henry, 'that could be us, that could be my husband, that could be my child ... I used to work on a paediatric ward.. the sicker the child the more I enjoyed it 'cos I felt I was useful now I wouldn't want to do that 'cos that could be my daughter'. This insightful maturity she was describing made me think of the first level theme, 'Own Learning'.

Ann also talked about how she interacts with patients whilst functionally treating them which over a period of time meant they would exchange information about themselves so she could become 'quite close I would suggest to some people'. She also recognised that 'you do get very closely involved with the carer, as much as the person themselves' which allowed her to appreciate the loss they must feel when their partner dies. She stated that each person with MND was different, an individual and how she did not expect them to fit in with her but learnt it was her role to 'change depending on what they're like' as she was not as vulnerable as them and she was only there to meet their needs. She was talking about 'fitting in' to where they were, if they were sad she would act quietly and respectfully, if they were jolly and loud she would join in with it. This issue of reacting to patients emotional state and character had been talked about by many other health care professionals so I was not surprised to hear this sort of dialogue again.

APPENDIX 7A

SECOND GUIDED CONVERSATION STORY FROM PC SEVEN

I did not enter the house for the second time with too many questions for clarification as I felt that from my experience of appreciating the stories of the people with MND, lay carers and at this point six other professional carers, that I was more than attuned to possibilities and realities as perceived. I began with going through my first level themes and there was little objection to any of them. When I asked her about the 'Own learning' theme this was modified a little as although she agreed that her own learning growth had been high on first meeting people with MND in the functional capacity that it was more than that, it was the whole issue of continually being open but willing to learn how to care. This phase 'Learning how to care' seemed a much more explicit and robust title to describe her experiences and so this was used to describe the negotiated second level theme. It offered more of a sense of learning from patients in the experiential setting.

When I suggested in her relationships with people with MND and their lay carers that she was driven to fit in with the person rather than have them respond to her she agreed with this interpretation. I them discussed with her how other health care professionals had offered me similar accounts of their behaviour and intentions in this area and that I was beginning a tentative cluster category of 'acting' or 'being a chameleon'. During this dialogue however, I acknowledged that it was difficult to offer a word or phrase that could capture this approach to patients and their carers. It was only later when I had concluded my conversation with Ann that the word demeanour came to mind which I used as the second level theme 'responding to the patient's demeanour'

APPENDIX 8

MND ANALYSIS: STAGES D2 -D3

D2. Cluster similar themes from each individual to form individual categories.

D3. Construct categories for each group from the themes and categories of the individuals.

D2

D2. Individual categories from MND 1

MND1 The shock of MND
MND1 The shock of MND
MND1 Initial clues of something wrong
MND1 Disappointment in the telling of the diagnosis

MND1 Forced life changes
MND1 Physical limitations of disease -Forced life changes
MND1 Increased isolation as disease progresses
MND1 Frustration of seeing people not understanding him
MND1 Recognition of outcome - death
MND1 All consuming restrictions of the disease on the person
MND1 Importance of controlling self, which is disappearing
MND1 Emotional labour to keep in control

MND1 Time closing in
MND1 The problem of time closing in
MND1 Fears

MND1 Limitations of others help
MND1 Attitudes required of professional carers
MND1 Realising the limits of the professional's interventions
MND1 Recognising other people's reaction to him

MND1 Knowledge adds meaning
MND1 Importance of learning about the disease
MND1 MNDA - the giver of hope

MND1 Adjusting to being cared for
MND1 Adjusting to being cared for - hard work itself
MND1 Progressive loss of self in tandem with progressive communication deficits
MND1 Watching body decline -caring for own body

MND1 False normality
MND1 Striving for normality
MND1 Uncertainty of progression

MND1 Relationship concerns
MND1 Concern for his wife - the burden of guilt
MND1 Affects on relationship with wife

MND1 Talking promotes reflection and reflexivity
MND1 Promotes reflective thinking
MND1 How others see you

D2. Individual categories from MND2

MND2 Horrors and uncertainty of MND
MND2 Realisation of something wrong
MND2 The telling by the Consultant
MND2 Horrors and uncertainty of MND

MND2 Knowing deterioration
MND2 Knowing physical deterioration
MND2 Sadness
MND2 Crying as a release of pressure

MND2 Knowing others for support
MND2 Professional carers - importance of 'knowing' them
MND2 Social carers as friends - 'I'm very lucky
MND2 Personal and practical help from MNDA

MND2 Importance of given time and setting goals
MND2 Importance of being given time
MND2 Coming to terms with the disease
MND2 I feel like a clock that's running down
MND2 The future - no need for plans only goals

MND2 Information and experiential knowing
MND2 Need for information
MND2 Affects on her from previous role models of coping

MND2 Re-establishing a normality
MND2 Trying to keep some normality

MND2 Learning how to be cared for
MND2 Learning from experience
MND2 Protecting self and others
MND2 Fighting spirit
MND2 Accepting help but not being forced
MND2 Fears
MND2 Hope and negotiating the level of help
MND2 Importance of being cared for to maintain energy levels for son
MND2 Lay carers (from social carers)
MND2 Society's caring behaviour

MND2 Relationship problems
MND2 Marriage difficulties

MND2 Reflection clarifies situation
MND2 Clearer in my own mind
MND2 Brings it in perspective

D2. Individual categories from MND3

MND3 MND - Destroyer of life
MND3 MND - Destroyer of life as it was
MND3 Being told of diagnosis
MND3 Slow beginning of physical decline- loss of function, re-inventing himself all the time

MND3 Learning gratitude and tolerance
MND3 Learning from experience
MND3 Grateful to be cared for - loss of critical rights
MND3 Reluctant receiver of care
MND3 Challenges in caring
MND3 *Effects of being cared for
MND3 Core of 'being' remains the same

MND3 Need for a sense of control
MND3 His reactions to physical dependence - need for control
MND3 Keeping control of aspects of his life
MND3*Value of working
MND3 Importance of physical equipment - control

MND3 Searching for reasons and meanings
MND3 Loss and gain - searching for reasons and meanings
MND3 Emotional changes (shock- deflection of the horror)
MND3 Fears

MND3 Pretence of normality
MND3 Pretence of normality
MND3 Lay carer trying to maintain normality - give him some control in his life
MND3 Certainty - Uncertainty: Powerlessness of both

MND3 Living for the moment in time
MND3 Predictions - Pretence and Living for the moment in time

MND3 Knowing others for support
MND3 *Other's impressions of him
MND3 *Others patronising reactions to him as he deteriorates
MND3 Fear of involvement frightens other people
MND3 Faith in her (lay carer) knowing him
MND3 Cared for helping the carer
MND3 Finding ways of hope

MND3 Changes in relationships
MND3 They are mourning my death - existential tuning in to others
MND3 Changes in relationships - loss of status
MND3 Changes in relationship - distancing from the children
MND3 Sharing his distress - talking about his pain

MND3 Exposure through reflection
MND3 Helpful but removes the mantle

D2. Individual categories from MND4

MND4 Journey through the diagnosis
MND4 Journey through the symptoms
MND4 Waiting for a diagnosis
MND4 Knowing before being told
MND4 Acceptance of diagnosis
MND4 Thoughts about MND

MND4 Constraints on life
MND4 Physical constraints
MND4 Restrictions on life
MND4 Resigned self in overwhelming adversity
MND4 Coping to live with it

MND4 Need for a normality
MND4 Situation too painful -remain in normality
MND4 Approach required of carers - normality of effort

MND4 Learning acceptance of loss and gain
MND4 Attitude to being helped
MND4 Kindness from others
MND4 Planning ahead for being cared for
MND4 Acceptance of change
MND4 Loss and gain

MND4 Need for others
MND4 Reliance on others
MND4 Functional professional carer involvement

MND4 Strength from purpose
MND4 Strength and deflection from self in having a young son

MND4 Search for information and meaning
MND4 Information search -MNDA

MND4 Reflection exposes reality
MND4 Talking makes it harder

D2 Individual categories from MND 5

MND5 Journey to the diagnosis
MND5 Charting the development of progressive loss of function
MND5 GP searching for a answer
MND5 Seeking diagnostic advice from family
MND5 Family offering mobility advice
MND5 Searching for a diagnosis
MND5 Telling the diagnosis - different approaches
MND5 Tension in diagnosis from the neurologist and neurosurgeon
MND5 Working out the diagnosis herself

MND5 Struggle for personal control
MND5 Loss and Gain
MND5 Loss of confidence
MND5 Role changes/Life changes
MND5 Struggle for independence
MND5 Progressive loss of physical body function
MND5 Powerlessness

MND5 Identification of criteria for 'good carers'
MND5 Professional support
MND5 Criteria for a good(professional) carer
MND5 Criteria for a good(lay) carer
MND5 The learning of being in a caring role (lay)
MND5 Criteria of not being a good carer

MND5 Learning to cope with caring
MND5 Learning to be cared for
MND5 Mutual care
MND5 Caring intentions for others
MND5 Being cared for
MND5 Caring for self
MND5 Reactions of others
MND5 Keeping spirits up (coping)
MND5 Learning to live with MND

MND5 Parcelling time
MND5 Parcelling time

MND5 Reflection promotes thought
MND5 Reflection promotes thought

D2. Individual categories from MND 6

MND6 The shock of MND
MND6 Knowing the diagnosis
MND6 Protection from shocking reality

MND6 Caring for family
MND6 Transition from denial to opening the door to it
MND6 Poor telling of diagnosis but it opened the door

MND6 Time and goals
MND6 Feeling after the diagnosis
MND6 Immediate goals requiring a fight for survival
MND6 Slow deterioration
MND6 Wishing for more time

MND6 Struggle for normality
MND6 Struggle for normality in an abnormal situation
MND6 Knowledge of medical matters makes it worse
MND6 transition
MND6 Coping strategies-linked to search for a normality

MND6 Importance of 'caring others'
MND6 Valuable aspects of MNDA Voluntary visitor
MND6 reciprocal caring
MND6 Family supportive but not emotionally
MND6 Importance of company : doing precludes thinking
MND6 Caring qualities - you have it or you haven't
MND6 practical aspects can be taught
MND6 reliability breeds safety
MND6 Criteria for good carers
MND6 continuity
MND6 good co-ordinator of the team
MND6 to be a person not a patientMND6 like minded and perception
MND6 respectful of what's happening
MND6 happy
MND6 poor caring
MND6 Professionals - be supportive

MND6 Loss and struggle for some control
MND6 Life changes -role change losses
MND6 loneliness
MND6 lost drams, unfinished business
MND6 lost independence
MND6 humiliating
MND6 Preparation for absence
MND6 sorting out the attic
MND6 closing her life, controlling it to the end
MND6 final preparations
MND6 Preparation for a declining physical future
MND6 PEG
MND6 Persona embedded in control and discipline

MND6 Frustrations in needing cared
MND6 Being cared for

MND6 needing to talk about it; emotional care
MND6 Effects of being cared for
MND6 Worries
MND6 Communication frustrations
MND6 Pain
MND6 Self-depreciating over physical difficulties -loss of control over physical functions

MND6 Meaning from suffering
MND6 Meaning out of her suffering
MND6 The future

MND6 Reflection raises awareness
MND6 Reflection raises awareness

D3

D3. NINE MND GROUP CATEGORIES BUILT FROM INDIVIDUAL CATEGORIES

Existential shock

MND1 The shock of MND
MND2 Horrors and uncertainty of MND
MND3 Destroyer of life
MND4 Journey through the diagnosis
MND5 Journey to the diagnosis
MND6 The shock of MND

Struggle with increasing loss of control

MND1 Forced life changes
MND2 Knowing deterioration
MND3 Need for a sense of control
MND4 Constraints on life
MND5 Struggle for personal control
MND6 Loss and struggle for some control

Temporal realisations

MND1 Time closing in
MND2 Importance of given time and goals
MND3 Living for the moment in time
MND5 Parcelling time
MND6 Time and goals

Strengths and limitations of received care

MND1 Limitations of others help

MND2 Knowing others for support
MND3 Knowing others for support
MND4 Need for others
MND5 Identification of criteria for 'good carers'
MND6 Criteria needed for caring

Importance of creating meaning

MND1 Knowledge adds meaning
MND2 Information and experiential knowing
MND3 Searching for reasons and meaning
MND4 Searching for information and meaning
MND6 Search for meaning from suffering

Learning to be cared for

MND1 Adjusting to being cared for
MND2 Learning how to be cared for
MND3 Learning gratitude and tolerance
MND4 Learning acceptance of loss and gain
MND5 Learning to cope with caring
MND6 Frustrations in needing cared

Dynamic normality

MND1 False normality
MND2 Re-establishing a normality
MND3 Pretence of normality
MND4 Need for a normality
MND6 Struggle for normality

Changing relationships

MND1 Relationship shifts
MND2 Relationship problems
MND3 Changes in relationships
MND4 Strength from purpose

Reality unmasked through reflection

MND1 Talking promotes reflection and reflexivity
MND2 Reflection clarifies situation
MND3 Exposure through reflection
MND4 Reflection exposes reality
MND5 Reflection promotes thought
MND6 Reflection raises awareness

APPENDIX 9

LC ANALYSIS: STAGES D2 -D3

D2. Cluster similar themes from each individual to form individual categories.

D3. Construct categories for each group from the themes and categories of the individuals.

D2

D2. Individual categories for LC1

LC1 Forced loss of personal freedom
LC1 Caring is loss of freedom
LC1 Demands of self
LC1 Everyday it's there
LC1 No escape
LC1 From wife to nurse
LC1 Restrictive life changes and role changes
LC1 Responsibilities for her

LC1 No personal resources to care about him
LC1 Importance of starting point in caring for others
LC1 No inner resources for coping with caring
LC1 Learnt from experience to dread caring for another
LC1 No real experience of doing caring- what is it?
LC1 Need for problem-solving skills
LC1 Aspects of practical help of caring more manageable
LC1 I don't try any more (conversing)
LC1 Unexpected mixed emotions

LC1 Searching for answers
LC1 Searching for answers about MND
LC1 Challenging time seeking diagnosis
LC1 Love for him helps acceptance of situation

LC1 Isolation in caring (suffering)
LC1 Isolation of carer
LC1 Friends withdraw
LC1 Friction and distancing resulting from his communication problems
LC1 Loss of speech = loss of the person

LC1 Caring for self
LC1 Become harder to protect self
LC1 Values change when challenged
LC1 Cheerfulness is the breath of life
LC1 Importance of family support

LC1 Strengths and limitations of professionals
LC1 Initially professional carers not listening
LC1 Change of doctor as Henry needed to talk
LC1 Supportive to have professional carers to call on
LC1 There's no organisation
LC1 Timing of equipment

LC1 Preparing for loss
LC1 Changes in him: loss of her partner already
LC1 Rapid physical changes
LC1 Preparing for his death
LC1 Humour extinguished
LC1 Anticipatory grief
LC1 To plan is to live, there is no positive planning now
LC1 Uncertain future for both of them

LC1 Reflection emphasises powerlessness over MND
LC1 It emphasised the problem
LC1 Powerless so why talk too much as you see the worst of everything

D2. Individual categories from Lay Carer Two

LC2 Knowledge fuels fear of MND
LC2 Gained knowledge of disease
LC2 Worse than cancer

LC2 Caring is hard work (suffering)
LC2 Detail positioning demands in physical caring
LC2 Coping and caring
LC2 Physical focus to his care
LC2 She's more emotional/He's more irritable

LC2 Loss of own life
LC2 Loss of personal freedom
LC2 Loss of lifestyle
LC2 Broken sleep/ Night time disturbances
LC2 Isolating

LC2 Pragmatic personal resources
LC2 Just got to get on with it: intimate care
LC2 Certain pride in his caring achievements

LC2 Experiential learning
LC2 Learning through experience
LC2 Problem solving: baby analogies
LC2 Keeping her cheerful
LC2 Learning lifting from nurses
LC2 Respecting wishes of the cared for

LC2 Normality before reality
LC2 Caring routine: keeping a sense of routine for normality
LC2 Not talking about MND to denying it
LC2 Push MND to one side/seeking normality
LC2 Avoid talking about MND
LC2 Symptoms talked about to problem solve but not the overall disease
LC2 Inevitability of outcome- forced acceptance
LC2 He's controlling of her emotions by not talking about it

LC2 Need others to help in care
LC2 Need relief from caring; friends sitting with her
LC2 Need others to help with the caring
LC2 Hopes for a holiday
LC2 No time for him being ill
LC2 Sneaking time for himself

LC2 Strengths and limitations of professionals
LC2 Problem-solving professionals valued as caring
LC2 Regular contact is valued as caring
LC2 Immediate response is valued as caring
LC2 Concerned attitude
LC2 Limitations of interventions of health care professionals- (we get on with it)
LC2 Rejection of non-carers Consultant; don't want to see him anymore really: not caring

LC2 Reflection taught him nothing new
LC2 There's nothing you can do about it
LC2 No, learnt nothing, not affected

D2. Individual categories from Lay Carer Three

LC3 Angst of terminal disease
LC3 Beginnings of MND
LC3 Self-diagnosis
LC3 Getting the diagnosis
LC3 Hatred of MND

LC3 Life changes
LC3 MND taking over and changing my whole life
LC3 Full-time job
LC3 Taking over my whole life- talked about it a lot
LC3 House adaptations imperative
LC3 Total physical care: *her physical effort/her feeding effort*
LC3 Shifting roles, with reluctance
LC3 Established new role for herself
LC3 Henry's physical abilities decline = more work for her
LC3 Changes in Henry's family control ability

LC3 Negotiating a rationale for the situation

LC3 Trying to redress the balance of good and bad happenings
LC3 Looking for the silver lining -more time but less time
LC3 Not feeling sorry for self as has so much from life

LC3 Temporal shifts
LC3 Parcelling the future
LC3 MND takes away your future
LC3 Live for each day

LC3 Re-creating normality
LC3 Different but same - normality
LC3 Striving & working for normality
LC3 Importance of normality for children

LC3 Personal resources to cope with caring
LC3 Use of humour :coping strategy
LC3 Problem solving skills
LC3 Learning new skills/finding her resources to care
LC3 Rising to the challenge for personal reward/pride
LC3 Love for her husband
LC3 Knowing her husband
LC3 Importance of emotional ties- love in knowing the person
LC3 Personal growth - increased confidence changes in her

LC3 Suffering of lay carers
LC3 Dependency & suffering from emotional involvement
LC3 Emotional angst : the worst side of things - emotions
LC3 Learnt to suppress emotions
LC3 Sadness from lost dreams

LC3 Caring for each other
LC3 Protecting each other
LC3 Henry's caring for her
LC3 Her caring for Henry: *Happier at work, mind occupied*
LC3 Protective of him when with others
LC3 Concern for others

LC3 Need for support in caring
LC3 Social carer support
LC3 Social outlet for herself
LC3 Disturbed nights - seeking help
LC3 Children helping her
LC3 Professional supporters

LC3 Support from professionals
LC3 Informed through case conference
LC3 Technical/practical support
LC3 Genuine knowing what it might be like for them

LC3 Comparison to GP without understanding

LC 3 Preparing to move on
LC3 Shifting approach to situation through time
LC3 Reclaiming her life, moving on

LC3 Sharing through reflection
LC3 Talking helps me think things through
LC3 I enjoyed it
LC3 Talking helps shift it onto the other, better when don't know them well

D2 Individual categories from Lay Carer Four

LC4 Heightened uncertainty of life
LC4 The journey towards a diagnosis
LC4 Hopeful she was wrong about diagnosis
LC4 Heightened uncertainty in life
LC4 Slow physical deterioration

LC4 Importance of information
LC4 Importance of information in life decisions
LC4 When a physical problem apparent they met it head on

LC4 Striving to maintain normality
LC4 Her interests keep her occupied
LC4 Importance of caring for son, deflection from her deterioration and caring needs
LC4 Liz achieving some independence
LC4 Son caring for Liz: normality
LC4 Search for normality
LC4 Avoid confronting the disease to maintain the normality

LC4 Doing precludes thinking
LC4 MND unfair/causes powerlessness: get on with it rather than talk about it
LC4 Doing precludes thinking about it
LC4 Keeping ahead of the disease

LC4 Forced restrictions
LC4 Life changes for him - extended roles and restrictions: losses for him
LC4 Lifestyle changes: losses and gains but rather have yesterday
LC4 Loss of personal freedom in caring
LC4 Life restrictions

LC4 Temporal pressures
LC4 Time pressures
LC4 Time is precious
LC4 Fearful of the future caring demands

LC4 Need for support in caring
LC4 Friends shocked and upset but supportive

LC4 Powerless over MND

LC4 Learning to care from professionals
LC4 His need to learn how to care *(from professionals, business like rather than emotional, learning to care from Liz (knowing her)*
LC4 Links with professionals
LC4 Empowered by professionals
LC4 One professional to contact is desired

LC4 Their partnership approach to caring
LC4 Respecting her autonomy, *Use her to inform him then he responds*
LC4 Partnership rather than carer
LC4 Protecting each other
LC4 Liz caring for him
LC4 His ideal of caring; time and following the cared for's needs
LC4 Relies on her fortitude

LC4 Emotional vulnerability
LC4 Their bad time is evenings, emotionally vulnerable

LC4 Life after loss
LC4 Thinking of his future after her death
LC4 Protecting self
LC4 Tensions pulling between work and caring for wife

LC4 Revelations gained from reflection
LC4 Realise I don't talk to my wife enough about it all
LC4 Realise I'm too practical not emotionally supportive

D2. Individual categories from Lay Carer Five

LC5 Forced personal losses
LC5 Personal loss of hobby: no time for it
LC5 Restricted to house more
LC5 Loss of freedom
LC5 Caring is a full time job
LC5 *Not just a routine but a chore
LC5 Whole life changes: different roles

LC5 Suffering demands care for the carer
LC5 It hurts but need to get on with life
LC5 Carers need help and support too
LC5 Care for self: *Need time relief*
LC5 *His deteriorating health from caring
LC5 Wife caring for him
LC5 Effects of caring exhausting, no time for self

LC5 Learning to care
LC5 Learning to care practically
LC5 Learn to think of the cared for : shift focus from you to them : Fear of Nursing homes

LC5 Learning to manage her and household
LC5 Problem solving

LC5 Temporal concerns
LC5 Take day by day
LC5 Timing is the problem
LC5 Everything comes too late
LC5 He is constantly on call
LC5 *speedy dynamics of need
LC5 *professionals had no time
LC5 Need for anticipatory services
LC5 Immediacy is vital ingredient to client support

Need for professionals
LC5 Professional carers have no time
LC5 Professionals need to ask LC questions
LC5 Need concern and time from the professionals: Moral support

LC5 Emotional caution/stress area
LC5 Emotional caution with wife
LC5 Talking about MND is emotional

LC5 Value of MNDA's experiential knowledge
LC5 MNDA very helpful: need for specialists
LC5 MNDA more knowledgeable and available resources than professionals
LC5 Experienced people know (MNDA)
LC5 *Nobody knows enough about it (MND)
LC5 Spread the word: MND needs to be more known
LC5 *Need for research into MND

LC5 Reflection focuses reality
LC5 Brings it to reality, her life expectancy
LC5 Reinforced need for thinking ahead of the disease

D2 Individual categories from Lay Carer Six

LC6 Uncertainties of life
LC6 First signs of a problem
LC6 She knew diagnosis
LC6 Signs developing
LC6 Difficulty with securing the diagnosis
LC6 Thought she was drinking alcohol/speech slurring
LC6 Her reaction to being told the diagnosis: difference between guessing and being told
LC6 Feelings about MND
LC6 Disease affects everything that is uniquely human
LC6 Frightening stage of MND
LC6 MND; no chance

LC6 Denial of reality
LC6 Protecting him over the diagnosis
LC6 His reaction to diagnosis - denial/disbelief
LC6 Physical capabilities declining fast: cannot deny it any more, evidence there

LC6 Caring needs teamwork
LC6 Caring is about team work
LC6 Need a co-ordinator for care and services interpretation
LC6 MNDA positive support

LC6 Learning care strategies
LC6 Learning to care
LC6 His wife's learning
LC6 Physical care strategies

LC6 Centrality of Time
LC6 Time restrictions
LC6 Lay caring is about 'Time and pressure' 'Disappointment and frustration'
LC6 Coping strategies/Taking short term goals only
LC6 His work balancing time pressures

LC1 Forced changes on him
LC6 Changing lifestyle in work, social life an family life
LC6 Broken future plans
LC6*Sleep deprivation from two jobs (her and his work)

LC6 Preparing for loss
LC6 Time out together to acclimatise pending death and plan future strategy
LC6 Weighing up his present and future job situation and Pam
LC6 A future of grief - effects on him
LC6 Personal changes
LC6 *Look beyond her death;
LC6 Strength from spiritual life
LC6 MNDA realism of time left

LC6 Importance of goals and hope
LC6 Pam needs hope
LC6 Pam sets her goals to achieve (in time left)
LC6 Mutual caring in setting targets for instillation of hope
LC6 Advice received - keep ahead of the disease
LC6 *Her caring for him
LC6 Tenderness in caring as she is the other half of my heart

LC6 Reflection challenges thoughts
LC6 Useful talking about it
LC6 Challenged to think about my response

D3. TEN LC GROUP CATEGORIES BUILT FROM INDIVIDUAL CATEGORIES

De-stabilising impact of impending death

LC1 Dread
LC3 Angst of terminal disease
LC4 Heightened uncertainty of life
LC5 Shattered
LC6 Uncertainties of life

Searching for answers

LC1 Searching for answers
LC2 Knowledge fuels fear of MND
LC3 Negotiating a rationale for the situation
LC4 Importance of information
LC5 Value of MNDA's experiential knowledge
LC6 Answers from MNDA

Forced life changes in caring for another

LC1 Response to forced changes to lifestyle
LC2 Loss of own life
LC3 Life changes
LC4 Forced restrictions
LC5 Forced personal losses
LC6 Forced changes on carer

Learning through caring

LC2 Learning through doing /No personal resources to care
LC2 Pragmatic resources
LC3 Using personal resources to cope with caring
LC4 Doing precludes thinking
LC4 Learning to care from professionals
LC5 Learning to think like the cared for
LC6 Learning care strategies

The false normality

LC2 Normality before reality
LC3 Re-creating normality
LC4 Striving to maintain normality
LC6 Denial of reality

Temporal realisations

LC1 Timid of help
LC3 Temporal shifts
LC4 Temporal pressures
LC5 Temporal concerns
LC6 Centrality of time

The vulnerability of being a carer

LC1 Distanced from others/ Caring for self
LC2 Caring is hard work /Need others to help in care
LC3 Suffering of lay carer/Need for support in caring
LC4 Emotional vulnerability/spouse partnership approach to caring
LC5 Suffering demands care for the carer
LC6 Importance of hope and goals

Strengths and limitations of professionals

LC1 Strengths and limitations of professionals
LC2 Strengths and limitations of professionals
LC3 Support from professionals
LC4 Supportive professional interventions
LC5 Need professionals
LC6 Caring needs teamwork

Preparing for loss

LC1 Preparing for loss
LC3 Preparing to move on
LC4 Life after loss
LC6 Preparing for loss

Reflection highlights reality

LC1 Reflection emphasises powerlessness over MND
LC3 Think things through in reflection
LC4 Revelations gained from reflection
LC5 Reflection focuses reality
LC6 Reflection challenges thoughts

APPENDIX 10

PC ANALYSIS: STAGES D2 -D3

D2. Cluster similar themes from each individual to form individual categories.

D3. Construct categories for each group from the themes and categories of the individuals.

D2.

D2 Individual categories from PC1 SALT

PC1 Strengths of professional role
PC1 Knowledge and experience
PC1 Balancing risk and making judgements
PC1 Prediction and reaction in uncertainty
PC1 Aware how no communication means invisible person
PC1 Listening to patients to guide input/allowing patients to take control
PC1 You don't dwell on what you can't do, you dwell on what you can do'
PC1 Evaluation of input to patients
PC1 Share part of the journey
PC1 Ability to relate to people

PC1 Limitations of professional role
PC1 Finite parameters of technical effectiveness
PC1 Resource frustrations
PC1 Need to assess patients knowledge first

PC1 Educational imperatives; helping others learn to be cared for
PC1 Education for compensation techniques
PC1 Education for explaining physical symptoms
PC1 Experiential awareness through practice
PC1 Teaching other professionals

PC1 Primacy of the patient
PC1 Give time to a patient
PC1 Learn about the person
PC1 Focus in on a patient
PC1 Listening so patients unburden themselves
PC1 Take on their burden of grief
PC1 Awareness of patient's stage of journey with disease
PC1 Recognition of the need for 'normality'

PC1 Reflection made thinking time
PC1 Made me think, don't normally have time
PC1 Difficulties of personal identification with patients

D2. Individual categories from PC2 Nurse specialist

PC2 Striving for Ideals in care
PC2 Wanting to provide the best that there is
PC2 Personal values guide professional behaviour
PC2 Personal reward from small successes
PC2 Strive for holistic benefit
PC2 Sense of responsibility in being a professional carer

PC2 Holistic stance towards the patient
PC2 Put locus of control with patient
PC2 Holism approach needed to help them live their life
PC2 Responsive to MND/LC stance
PC2 Individualising professional judgements

PC2 Limitations to professional caring
PC2 Economic pressures in care
PC2 Health and social care interface
PC2 Realistic of professional limitations for action
PC2 Need experience of MNDA
PC2 Lack of effective speed

PC2 Importance of inter-professional communication & co-operation
PC2 Importance of co-ordination of professional team
PC2 Professional liaison

PC2 Openness to learn
PC2 Openness to learn how to care
PC2 Listen to guide action
PC2 Understand spouse and patient's situation

PC2 Reflective evaluation
PC2 Made me think, be reflective

D2. Individual categories from PC3 District nurse

PC3 Ideals in caring
PC3 Ability to show people they matter
PC3 Put the illness in an holistic context
PC3 There for them both (spouse and patient)
PC3 Respect their autonomy
PC3 Maintain a normality of life
PC3 Honour promises and don't make those that cannot be kept- honesty

PC3 Learning through caring
PC3 Learning through experience
PC3 Breaking the 'rules'
PC3 Learning about the disease
PC3 Doing your best allows acceptance of death outcome

PC3 Sensitivity with communication challenge

PC3 Limitations to professional caring
PC3 Lack of economic funding
PC3 Terror of the disease
PC3 Importance of MNDA

PC3 Responsive friendship
PC3 Aware of your visitor status
PC3 Focused temporal friendship
PC3 Trying to fit in with their lifestyle
PC3 Temporal priorities
PC3 Emotional labour

PC3 Inter-professional co-operation
PC3 Case conferences to appreciate professional boundaries
PC3 Inter-professional co-operation
PC3 Teaching other professionals

D2. Individual categories from PC4 Dietician

PC4 Functionalist professional approach
PC4 Purpose of meeting nutritional needs
PC4 Aim for quality of life in nutritional sphere

PC4 Novice learning about care
PC4 Learning from own and others' experience
PC4 Problem solving the unexpected problems
PC4 More contact time promotes memory of family
PC4 Positive rewards to self of helping
PC4 Remaining functional reduces personal stress
PC4 MND gives her a sadness

PC4 Limitations to care
PC4 Role restrictions from time pressures
PC4 Inexperience in communication difficulties
PC4 Sadness of no cure

PC4 Inter-professional liaison

PC4 Ideals in caring
PC4 Respect their autonomy
PC4 Needing sensitivity without dwelling on situation
PC4 Usefulness of home visits
PC4 Awareness of carer struggle

D2. Individual categories from PC 5 Social worker

PC5 Ideals in caring
PC5 Share professional power to steer from an unequal relationship
PC5 Let's get this sorted
PC5 Commitment to care
PC5 Holism to support both partners
PC5 Respect persons
PC5 Promoting choice and autonomy with support
PC5 Personal qualities needed to care
PC5 Motivation to care through commitment

PC5 Functional role
PC5 Social packets of care for people to remain at home
PC5 Being realistic about care options

PC 5 Responsive friendship to meet patients needs
PC 5 Suspending own values for clients interests
PC 5 Following the patient's lead and needs
PC 5 Fitting in with patient's lifestyle
PC 5 Giving them time to talk
PC5 Client loyalty

PC5 Learning through experience
PC5 Learning through personal experience of care
PC5 Evaluation of care for change

PC5 Professional constraints to caring
PC5 Tensions between health and social care boundaries: management organisation
PC5 Complexity of MND & Social worker role: professional organisation
PC5 Speed and relentlessness of MND
PC5 Disability not valued in society
PC 5 Temporal urgency of MND not responded to by fund-holders
PC5 Economic constraints of poor resourcing

PC5 Importance of professional liaison
PC5 Professional liaison
PC5 Usefulness of case conferences

PC5 Reflection as thought provoker
PC5 Emotional impact of MND on social worker
PC5 Too busy usually, I just moved on until read transcript
PC5 Don't have a fast track strategy, which we need for people with MND

D2. Individual categories from PC6 GP

PC6 Ideals in caring
PC6 Motivated by wanting to be useful to people

PC6 Aim for shared partnership with patients

PC6 Learning about MND care
PC6 Learning about MND with patient
PC6 MNDA booklets

PC6 Limitations of professional role
PC6 Lack of experience with MND
PC6 Challenges of no cure to the professional carer
PC6 Hard to deal with MND as it is emotionally exacting
PC6 Communication difficulties with MND patient
PC6 Limited role as other PC's more involvement
PC6 Shortness of time to attend patients

PC6 Strengths of professional role
PC6 Reassuring authority of GP role
PC6 GP's role- reassurance through authority and prescriptions

PC6 Professional liaison
PC6 Importance of liaison with others
PC6 Case conferences for information
PC6 Strength of sharing a problem

PC6 Too busy to reflect
PC6 Too busy after interview, no effects
PC6 After second interview; Made me think I ought to phone lay carer (bereaved)
PC6 Not fully aware how things are affecting you

D2. Individual categories from PC7 Physio

PC7 Strategies to assist with impact of MND
PC7 Awareness of impact of MND
PC7 Honesty with information
PC7 Be grounded in patients world

PC7 Professional strengths
PC7 Physio role - functionalist and emotional
PC7 Initiate monitoring and supporting role
PC7 Liaison with other agencies
PC7 Value of MNDA
PC7 Recognition of the importance of lay carer role
PC7 Teaching others through discussion of insights

PC7 Learning sensitivity through experiences
PC7 Learning how to care through experiences
PC7 Importance of holistic assessment
PC7 Importance of locating self in caring for others

PC7 Altruistic values motivate caring
PC7 Sensitivity raised from working with people with MND/community
PC7 Impact of personal vulnerability - changing views of caring intervention
PC7 Holism in action- Care after death of patient

PC7 Responding to patients' demeanour
PC7 Responding to patients' demeanour- (emotional labour)
PC7 Problem solving limited communication abilities
PC7 Sharing the experience - common humanity but differing roles
PC7 See clients them together and separately

PC7 Constraints on professional role
PC7 Funding and equipment shortages
PC7 Frustrating slow bureaucratic processes
PC7 Lack of hospice involvement
PC7 Variation of individual professionals to team work
PC7 Little explicit valuation of caring
PC7 Professionals need support
PC7 Adapting to levels of seriousness in illness

PC7 Temporal focus
PC7 Adapting with time - Turning points
PC7 Priorities of seriousness
PC7 People need your time first

PC7 Reflective benefits
PC7 Interesting to talk it out and say it
PC7 Think about your feelings about people

D2. Individual categories from PC8 Neurological Consultant

PC8 Strengths of professional role
PC8 Finding the death sentence
PC8 Consultant's telling diagnosis /prescribing drugs
PC8 Judging stance and knowledge of patients
PC8 Liaison with other professionals
PC8 Teaching student doctors
PC8 Minimal interference

PC8 Limitations of professionals
PC8 Lack a counselling team member
PC8 Time short in OPD
PC8 Need for specialist nurses
PC8 Limited time for interaction with patients

PC8 Ideals in caring
PC8 Approach varies with each individual
PC8 Protection of patient -defer the diagnosis

PC8 Giving hope and reassurance
PC8 Give confidence and encouragement
PC8 Social interaction in relationship as well as medical
PC8 Understand what peoples concerns are
PC8 Reduce others' suffering
PC8 Importance of support for patient

PC8 Learning through experiences
PC8 Learning through experiences to tell people the diagnosis
PC8 Emotional effects on the consultant
PC8 Patients need answers and strategies
PC8 Understanding supersedes mode of communication
PC8 Listen to patients stand-point

PC8 No explicit reflection
PC8 Nothing specific, what's next, I've patients to see

D2. Individual categories from PC9 Occupational therapist

PC9 Professional strengths
PC9 Functional assessments, equipment and adaptation
PC9 Aim of care; maintain patient's normality
PC9 OT interventions for independence
PC9 Rapid response to diagnosis
PC9 Draw on MNDA experience and facilities
PC9 Case conferences/liaison with others
PC9 Experience with MND permits more forward planning
PC9 Adapting to patient's physical deterioration
PC9 Teaching others through practice

PC9 Weaknesses in service for MND patients
PC9 Need for a new counselling role
PC9 Need for an explicit pool of MND equipment
PC9 Health and social agency tensions
PC9 Lack of uniformity in care delivery/co-ordination
PC9 Powerless to stop physical decline of patient
PC9 End up monitoring decline

PC9 Ideals in caring
PC9 Make a difference to peoples' lives
PC9 Promotion of patients decisions in care strategies
PC9 Confidence and optimism needed for caring
PC9 Sensitive to their stage in the journey
PC9 Enabling them to talk through their feelings
PC9 Continue care for spouse after death of patient
PC9 Involvement generates professional stressors

PC9 Responsive close relationship
PC9 Relationship- close through time

PC9 Sensitive and responsive to patient/carers
PC9 Valuing and protecting the carer
PC9 Working together to achieve what they wanted
PC9 Identification of self with patient
PC9 Maintaining communication

PC9 Usefulness of reflection
PC9 Your questions were thought provoking so I thought about it a lot
PC9 I'm happier now we've gone through it
PC9 The points you've highlighted are very importance

D3

D3. EIGHT PC CATEGORIES BUILT FROM INDIVIDUAL CATEGORIES

Strengths of professional role

PC1 Knowledge, experience, judgements
PC2 Assessment of services to needs
PC3 There for him
PC4 Functionalist nutritional approach
PC5 Power to determine needs
PC6 Authority for action and to reassure
PC7 Functional and emotional
PC8 Finding, telling and judging
PC9 Assessment for independence and adaptation

Ideals of care

PC1 Primacy of the patient
PC2 Striving for ideals in care
PC3 Ideals in caring
PC4 Ideals in caring
PC5 Ideals in caring
PC6 Ideals in caring
PC7 Strategies to assist with impact of MND
PC8 Ideals in caring
PC9 Ideals in caring

Situated friendship

PC3 Responsive friendship
PC5 Responsive friendship to meet patients needs
PC7 Responding to patients' demeanour
PC9 Responsive close relationship

Learning through experience to care

PC1 Educational imperatives: helping others learn to be cared for
PC2 Openness to learn
PC3 Learning through caring
PC4 Novice learning about care
PC5 Learning through experience
PC6 Learning about MND care
PC7 Learning sensitivity through experience
PC8 Learning through experiences

Critical nature of time

PC3 Temporal urgency of action
PC6 Shortness of time for patients
PC7 Time focus
PC8 Support for short living time
PC9 Critical nature of time

Role limitations

PC1 Limitations of professional role
PC2 Limitations to professional caring
PC3 Limitations to professional caring
PC4 Limitations to care
PC5 Professional constraints to caring
PC6 Limitations of professional role
PC7 Constraints on professional role
PC8 Limitations of professionals
PC9 Weaknesses in service for MND patients

Importance of inter- professional co-operation

PC2 Importance of inter-professional communication and co-operation
PC3 Inter-professional co-operation
PC4 Inter-professional liaison
PC5 Importance of professional liaison
PC6 Value of professional liaison
PC8 Liaison with other professionals
PC9 Inter-professional co-operation tensions

Continuum of reflective thinking

PC1 Reflection made thinking time
PC2 Reflective thinking
PC5 Reflection as thought provoker
PC6 Too bust to reflect
PC7 Reflective benefits
PC8 No explicit reflection
PC9 Usefulness of reflection

APPENDIX 11

EVIDENCE SUPPORTIVE TO MND GROUP CATEGORY FINDINGS

This evidence is supportive to the findings presented in chapter 6. It is sequenced in accordance with chapter 6 (i.e. section 6.5., 6.5.1. etc) to facilitate orientation.

6.5. STRUGGLE WITH INCREASING LOSS OF CONTROL

This second category highlights the practical concerns and emotional realities of struggling with increasing debilitation. Loss of control pervades all aspects of their lives. Personal knowledge of bodily deterioration and a loss of physical control forces a person to struggle with facing death and day to day life. They try to maintain a sense of self through clutching to aspects of personal control in difficult circumstances. The six contributing categories are;

MND1 Forced life changes
MND2 Knowing deterioration
MND3 Need for a sense of control
MND4 Constraints on life
MND5 Struggle for personal control
MND6 Loss and struggle for some control

Increased loss of function forces life changes which is challenging to one's composure,

'you never like to think you are incapable of doing something and relying on somebody else.... You're annoyed. I try and keep it in myself really and normally it doesn't do any good blaming anyone. I can keep it under control ... some days are harder' (MND1)

When part of the body is threatened and functions differently, the whole person faces a threat to its integrity. This situation develops an increasing loss of integrity of the 'self'. The experience of bodily decline is bench-marked with memories of what life used to be and is seen as a sense of loss which the following two statements convey;

'It's annoying because there are so many things you can't do, things you used to be able to do and now you can't and that's a bit upsetting. I know certain things I am not going to be able to do again and that's upsetting' (MND1)

'When you can no longer stand and walk and your speech gets worse, that affects you more when that happens, that will upset you' (MND3)

As the disease progresses, the person's struggle heightens. MND6 recognised that although he wanted his wife's care he did not want her doing too much. His personal struggle and control which he had relinquished to her was now under threat of being taken out of his family context, 'I don't want her doing too much. Yet, I don't really want someone else to care for me but I don't mind people helping me but I don't really want someone else taking over my life from me' (MND3).

The extent of the growing struggle and need for others to help is illustrated by the following comments;

'I found I couldn't lift a kettle up to make myself a drink and I couldn't pour a cup of tea out' (MND5).

'I can't do so much physically. I get out of breath and my strength is going. I can't lift things like I used to do…everything I do is affected by it. There's nothing really I can do apart from watch television' (MND1).

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The human spirit seems to be able to continue the struggle in the face of terrible adversity, 'What a way to die, bit by bit like a crushing ivy killing off a healthy tree. I have a lot to do for my family before the last clutches of the deadly ivy zaps the last bit of sap' (MND6). However, the relentlessness of MND means, 'it's really taken over our lives' (MND3) to the extent of slowly winning by imposing exhaustion and depression; 'I'm getting very fed up with being ill, there's no respite' (MND2).

6.5.1. Implications of category 'Struggle with increasing loss of control'

Memories of pre-MND life are their base-lines for judging the pace and extent of their deterioration. Declining bodily function reflects the proximity of death. Remaining in the fight requires energy and becomes their focus. Consciously moving towards death whilst losing bodily control involves a negative sense of 'becoming', a slow loss of 'Being' in all its sense. Appreciation of this struggle is imperative for delivering quality supportive care.

Practical implications;

A: Cared For

- need for functional support as their own bodily control diminishes.
- loss of control is a need in itself and so strategies which promote self-control such as active decision-taking and choice are imperative for the sense of self

B: Lay Carers

- acceptance that loss of functional control is inevitable, undesired but essentially uncontrollable
- their work load and responsibilities increase directly to match their partners loss of function

C: Professional Carers

- immediacy of establishing a team of professionals to help with functional needs
- consideration of extra workload of lay carer should initiate an assessment of need, both physical and psychological

Philosophical implications

A: Cared For

- as the integrity of the bodily self diminishes the mental self suffers alongside. These losses are a threat to one's sense of worth and social interaction which may result in isolation, loneliness, frustration and despair
- an other is needed to share these losses with them, to listen, interact and demonstrate that they remain human beings and matter as much as when they were fully functional
- need for sensitivity and consideration from professionals who are supporting them in physical losses

B: Lay Carer

- the struggle also affects them; emotional pressures increase as they see their partner deteriorate and struggle
- they are pulled into the emotional angst which is coupled with exhaustion in offering physical and emotional support to their partner

C: Professional Carer

- need for awareness of the holistic loss of 'Being', the threat to the integrity of the 'self'
- need to promote choice and control in planning to support the mental self of the person with MND

6.6. TEMPORAL REALISATIONS

One participant aligned her body to a clock, 'Everything I do makes me feel tired. I feel like a clock that's running down (MND2)'. Time is central to her thoughts with the slowing down of her body seen as a mechanical tiredness, the symptom of coping with the physical and emotional distress. Being in time is her acute experiential reality which creates the category of 'temporal realisations'.

MND1 Time closing in
MND2 Importance of given time and goals
MND3 Living for the moment in time
MND5 Parcelling time
MND6 Time and goals

One's 'being in time' so often feels unending. The sudden realisation of one's impending death puts a sharp focus on remaining time and one's new attainment goals. Assumptions that goals can be achieved, that hopes may be met are often taken for granted. With MND the reality of time closing becomes clear in the most simple of life's actions as, 'even walking upstairs becomes more difficult and it makes you think, will I be doing this next year' (MND1). MND1 was dead six months after making this statement.

The realisation of the fragility of one's time led to living each day as it was, 'I think it helps by living almost a day at a time' (MND3). Parcelling time into manageable chunks that are safe, true and real, led to many participants actualising their time, 'I just take day by day' (MND5) as 'taking a day at a time keeps things in small bits that you can manage, cope with … set yourself little aims' (MND6). Thinking ahead is too painful as it offers a distressing picture of further physical deterioration, inabilities and death. In this manner, time still offers life and opportunity.

Goals are realised through time and they reflected on what they considered their 'being' to be about, having hopes, aspirations, plans, a future. Although in their minds they knew how limited their goals should be, in their hearts there were echoes of 'bargaining' with the disease or trying to instil self-hope;

'I don't think about the future too much. I want to reach the year 2000 but I can't (brief silence), it suddenly takes a downward dive and I feel ..oh.. and it just fills you up but I look ahead and that is, within my mind, I appreciate that I could go in six months ..I want to see my son grow up (quiet sobbing) and I'm determined to be here in the year 2000, albeit I might be in a wheelchair'' (MND2).

MND6 stated she did not feel angry about MND but felt cheated out of time. She was in her 50's and had expected to enjoy privileges of old age, 'Never angry ..very sad about this.... feel cheated.. wanted to see him (son) go through his life, become a Grandma and all these things' (MND6). Indeed Mrs MND6 had early insertion of a gastrostomy feeding tube into her stomach, before she was unable to swallow. Its purpose was to promote life by ensuring her nutritional strength when she was no longer able to eat and drink.

Temporal realisations linked time and goals as one sets dependant parameters. The following reflection of the researcher summarises this commonality,

MND1 did not want to be a burden to his wife. He knew she was unable to cope with his disability despite her efforts. Their relationship was sinking into one of basic existence only. She could not cope with his loss of speech. Language and communication were a central part of their relationship so they deteriorated into tolerance, non-communication and living in separate rooms. He identified her difficulties and realised the burden he was placing on her with his disease. Unexpectedly, he died within three months of diagnosis. An interpretation of this situation is that his goal was to relieve them both of the burden and he gave up the will to fight for further time.

In brief, the other participants also stated their time-related goals.; MND 2 wanted to see in the year 2000 when she would be able to see her son grow a little more into adolescence and felt her son would be old enough to cope with her death better. MND 3 wanted to remain at work for as long as possible to distract him from his situation. He managed to achieve this by still working up to three days before his death. MND 4 on being told of the diagnosis purposefully became pregnant and found caring for her young son an enormous deflection from her own problems.

6.6.1. Implications of category 'Temporal realisations'

The MND participants have an acute awareness of the preciousness of time. This is linked to a sharp re-focusing of goals as to what was important to them to sustain hope and reduce their suffering. There is evidence of bargaining with life which firmly locates these people on the death and dying trajectory as well as in disability. Goal setting can be viewed as a way of caring for themselves. Any achievements can contribute to dealing with the suffering, sadness or depression by seemingly taking control over their life.

Practical implications:

A: Cared For

- the realisation of time running out stimulates a rapid assessment of what is important to complete before departure
- people with MND need to be supported to remain functional for as long as possible to strive to achieve their stated goals
- spoken goals offers a target for them and others to work towards and re-establish a sense of hope and personal control

B: Lay Carers

- need to expect the possibility of goals being presented to them from their partner.
- goals ideally can be encouraged to be realistic to their possible time frame. (Some goals may have direct effects on their lay carer who may be asked to pursue the goal as a proxy if it is not completed before their death)

C: Professional Carers

- awareness of the possibility of goals being set by patients
- consideration of the pressure the goals may place on the lay carer
- efforts to physically support the patient to achieve their goals with realisation of the critical nature of time for these people

Philosophical implications:

A: Cared For

- are located in their sense of hope. Achievement of goals or the planning of goals can be for preparatory closure and 'letting go'
- are linked to the process of dying, incorporating shock, anger, bargaining and suffering through impending loss. Such loss is of function, self and Being. They are about to lose everything and their goals can serve as a gain in this equation
- interest and support in a person can stimulate goals and hope which may be linked to time span

B: Lay Carers

- taking an interest and supporting their partner can stimulate goals and hope which may be linked to time span

C: Professional Carers

- recognition and support for goals as being a vehicle for patients to re-gain a sense of control and hope which may be linked to time span

6.7. LEARNING TO BE CARED FOR

At first sight it may be considered unusual that one has to learn how to be cared for. This category captures the acute change in circumstances MND creates for people as they have to learn new skills and a new way of Being.

MND1 Adjusting to being cared for
MND2 Learning how to be cared for
MND3 Learning gratitude and tolerance
MND4 Learning acceptance of loss and gain
MND5 Learning to cope with caring
MND6 Frustrations in needing care

Learning to be cared for involved a transformation of 'Being'. They had to learn 'how' to receive care in the physical sense and the psychological sense of learning 'gratitude and tolerance' towards others for attending to their vulnerability and passivity. They had to learn much about loss in terms of their rights and independence.

First however, they had to learn to accept they needed help. As one MND participant put it, 'I've been a very independent person and it's hard to accept help but I feel if you can, it's a certain help… coming to terms with the fact that you do need help and once you realise it, it's not to keep denying it' (MND2). The denial of help could be associated with the denial of MND.

People found it hard accepting their physical deterioration with the subsequent physical interventions of being washed, shaved, dressed and fed and using a wheelchair. A strong frustration was the potential and actual invasion of privacy. One particular fear of being cared for was to find yourself 'not coping in the loo.. tremendous fear' *(MND6)* which was closely followed by the prospect of being bedridden.

These feelings of vulnerability and loss of privacy led to an overall dislike of being cared for which was coupled with learning about the effects of losing independence;

'I don't really like it..... I've always been able to do things for myself and relying on other people I don't really like. I have to be more tolerant' (MND3).

Having to learn tolerance was not confined to the physical interventions as their communication difficulties presented them with enormous frustrations, 'when you've not been understood, that's really one of the hardest things' which can lead to feelings of 'humiliation' (MND6) as they struggle with increasing inability to interact with the world.

The MND participants acknowledge that these hard lessons have to be learnt in order to accept and cope with being cared for. Moving from a situation of independence and self-determination to that of dependence, they did not find natural. Their need to exercise tolerance and learn to accept their increasing loss of independence was forced upon them and sometimes meant giving up one's rights as if 'she does not do something quite right I don't want to say' (MND3).

A particularly challenging feature was learning to adapt to a range of carers. The cared for disliked the constant change they experienced in caring personnel. They found it unsettling as they had to keep reacting to differing personalities and styles of care. The cared for felt it was usually up to them to adapt to ways of the 'new' carer rather than vice versa. Two quotations explain this,

'they've got their own way of doing things and I've been used to someone doing it my way but I will, do fall in with them when they've got different ideas' (MND5).

'It's hard having strangers in your home doing things... the more you know someone, the more you can say, 'Well, do you mind, I like it done like that'. But saying that to a complete stranger!' (MND2).

Their loss of control and forced adaptation to outside care was tempered by their recognition of how demanding the practicalities of caring was for their partners. They learnt to accept it as a way of caring for their carers.

'I've been thinking about it, well mostly how hard it is, both physically and emotionally.... 'my wife has to bathe me, she may be tired after bathing me but she carries on doing it and I'm no flyweight either... I don't want her doing too much. Yet I don't want someone else' (MND3).

Often they were torn with this desire to be cared for by their spouse but acknowledging the pressure this puts on them.

6.7.1. Implications of category 'Learning to be cared for'

The MND participants did not like being cared for as it involves loss of privacy. The need for caring emphases one's vulnerability and loss of control. Being cared for requires expressions of gratitude and tolerance even when they are resisting their situation but these 'learned ways of being' are to promote the social/professional carers to continue which removes pressures from their partners. Learning to accept care is a struggle that can be linked to accepting the disease and its implications

Practical implications

A: Cared For

- being cared for is disliked. A continual tension in this area can create more exhaustion and frustration
- accepting the disease and therefore the caring may need time
- adjustments will need to be made to many practical aspects of life and these need to be considered, debated and when possible agreed with the recipient
- appropriate action made with choice remaining with the cared for, for as long as possible
- consistency of all carers is desired
- awareness of the pressures on lay carers, as caring is hard work may promote acceptance of other carers
- communication difficulties exacerbate feelings of vulnerability and make acceptance of caring harder, particularly if carers change

B: Lay Carers

- resistance to social carers may be worse if personnel changes are frequent
- 'supervision' by lay carers of contact with social/professional carers may be supportive for partners who have communication difficulties
- emotional frustrations may be met with increasing loss of independence by their partner
- the link between accepting the disease and caring may need time

C: Professional Carers

- patients experience anxieties concerning challenges to privacy, this needs effort to reduce these challenges
- promote continuity of care at all times - team approach important
- when there are communication challenges, always speak to the patient but involve the lay carer to help interpret so the cared for is always heard
- lay carers need support with practical interventions of learning care, in addition to the patient

Philosophical implications

A: Cared For

- accepting care may be linked with accepting MND
- knowledge that adjusting and learning to care are 'normal' features of having a disabling disease may help in this phase of a change of 'being'
- challenges to privacy can be debated with carers to develop strategies to minimise them
- vulnerability and loss of control are inevitable outcomes of being cared for; they are a shift in one's state of being
- awareness of the stress on partners in caring is important but this needs to be balanced with the patient's need to preserve their 'voice'
- communication difficulties can render patients more out of control and vulnerable as they cannot express themselves. In preparation for this and to reduce these feelings, set up a written introduction of yourself, your preferences and dislikes in many situations for a range of audiences

B: Lay carers

- awareness that partners acceptance of care may be linked with accepting their disease
- the stress of caring for a partner may be enhanced if they resist your interventions. Need to discuss the ways of being patients prefer
- need for awareness and sensitivity of partner's anxiety concerning challenges to privacy and dignity with effort made to reduce these challenges
- as communication difficulties become more profound partners may withdraw. Need to plan future communication strategies
- awareness that more social isolation occurs as patient communication decreases

C: Professional carers

- need awareness that for patients to accept care, this may be linked with accepting their disease

- need awareness that patients are being forced to learn how to be cared for. It is a threat to them and disliked (if they react against it, it is not necessarily personal)
- lay carers will be exhausted by the effort of caring and have their own needs
- communication challenges do not remove the person from the caring focus

6.8. CHANGING RELATIONSHIPS

The previous category clarifies how the need for caring creates role changes between partners, in caring the dynamics of a relationship change. These changes can create problems as well as offer areas of strength.

MND1 Relationship role shifts
MND2 Relationship problems
MND3 Changes in relationships
MND4 Strength from purpose
MND5 Abstention from role
MND6 Diminished role

MND1 realised how his deterioration was putting pressure on his wife as 'she is having to work for two people and I'm just sad at letting her do it'(MND1). He took ownership of this as 'I mean you don't like to see your spouse with problems and I am making them for her, so that's very emotional' (MND1). Within this relationship, the forced role shift was received negatively by both parties, particularly when his communication ability diminished. They had been used to discussing world news, sharing ideas and minds but the tensions of his communication deficits and her increased responsibilities led to her patience being eroded. This leads to conflict as they used to 'comment on things like in the newspaper (and) by the time I've tried to say something it's advanced on' (MND1). Their roles had shifted and their relationship seemed to have lost its direction, purpose and meaning. A significant part of this change in relationship can be liked with loss of self. The loss of original self was embodied in their loss of role. This led to isolation which in turn was compounded by loss of communication;

'I was able to make myself understood but now when I talk to people they look a bit puzzled and I can see I haven't got through, even my wife has problems in understanding what I am saying.. as time goes on I am losing my voice and it is difficult to converse ...(it) makes people a bit dubious about talking to me' (MND1)

MND2 was in a difficult marital relationship prior to the onset of her disease. MND made things worse. Management of household duties became more difficult so her reliance on her husband increased only for him to respond with uncertain outcomes,

'If he wants to do something and he feels good about it he can be very happy doing it but if I suggest doing something he runs the other way a mile and so I asked him at the weekend to bring in the shopping from the car, and could he take the washing off the line, I was told to stop giving him orders...... but another time, two days later I was having a good cry and he came in and said, 'We've got to face this together' and that made me smile and I thought, but how much is together' (MND2).

MND3 found his changing relationship with his family devastating as he 'was head of the family, now I'm not' which he reports as 'not very satisfactory' (MND3). His wife was developing new confidence and skills of managing household finances, driving a new car which could take his wheelchair, organising the children going to school and getting her husband to work. He was slowly removing himself from the family conversations, unable to eat the family meals and not being consulted by the children. He reflected how he felt the children were preparing for his death. He explains he can see the grief in their faces and their sadness when they are near him, 'I think also in a way I feel that I am leaving and that they are mourning my death' (MND3). However, he tried to use work to maintain a sense of stability in some of his relationships and indeed did work up to three days before his death. He stated 'my work helps enormously... yourself is wanted by other people' rather than being dismissed and becoming isolated.

MND4's relational changes were diminished by there being a person requiring more assistance than her in the household, her toddler son. A growing toddler meant change was inherent in the household, 'I think things change anyway with Peter my son' (MND4). So as her husband and parents took on more responsibilities, this was under the guise of it would naturally occur. Their child acted as a decoy to her physical deterioration. Indeed, her son gave her a new role and a great strength as 'I think you think more of him than yourself' (MND4).

Changing relationships was transparent in a household of two elderly people where the relationship changed from a 'traditional' wife and husband scenario with the husband expanding his role. MND 5 soon became chair bound but,

'I was doing everything. I was doing all the cooking. I'd walk down the garden until March this year and I was trying, trying to do things that I could in the garden because I was a very keen gardener ... he (husband) does all the cooking and all the work now' (MND5). She would offer advice, when asked, from her chair but could do no more.

The notion of role abstention and its effect on role relationship is also exemplified by MND6. She was the pivotal role in the family, the 'spider in the middle of a web', caring for her family, her elderly mother and keeping the house together. Her physical deterioration reduced her capabilities and this led her to 'feel a waste of space.. useless' and makes her 'cross with yourself, you cut yourself off'. and contributed to her feeling of isolation.

6.8.1. Implications of category 'Changing relationships'

MND hijacks the person; their roles, relationships and ultimately their way of Being in the world. Through witnessing their own physical deterioration and communicative isolation their roles diminish and their relationships shift with others and themselves. This leaves the person with MND almost in a state of 'anomie', with no future prospects but death. They are dying, as are parts of their relationships with others. Their role shifts and abstentions are rehearsals for their permanent absence. The feeling and reality of 'being cut off from life' seems to be the pivot of changing relationships.

Letting go roles can result in relinquishing relationships. As one finds the roles which defined you are no longer yours there is a loss of original self. The loss of original self makes you into a different being and the practical and emotional relationships with others can become unbalanced. This creates a dual problem, loss of self and potential increased isolation from others. The result can be a lonely useless existence whilst waiting to die.

Practical implications

A: Cared For

- relationships are naturally dynamic at the best of times and usually involve a give-and-take premise. Where the give reduces in some areas, it may be possible to increase it on others - more thinking strategies than doing strategies
- promotion of previous roles when at all possible reduces the impact of the physical deterioration on the self.
- the loss of ability to fulfil roles eventually means the roles need to continued by someone else: perhaps if this is achieved through negotiation it can be a little more manageable for them
- clear transference of responsibilities may offer a relief for the carer and a sense of purpose and worth for the cared for

B: Lay Carers

- as the partner's ability to perform roles diminishes, this places more demands on the carer in household responsibilities which might mean more external help is required and new skills need to be learnt

C: Professional Carers

- knowledge of the role and relationships before onset of disease need to be known to appreciate the stressors the person with MND and their partner are undergoing
- changing relationships may place affect care delivery by lay carer to spouse and mean more external support is required

Philosophical implications

A: Cared For

- loss of role is linked with loss of self which changes the dynamic of relationship
- loss of 'self' through altered definition of role is linked with potential loss of life and preparing to leave the relationship through death
- the threat to one's Being as previously defined needs help to remain in the world - the human being could be lost without a valuation of the person who still is
- relationship counselling may be one route to examining the psychological and emotional interplay in this disease, between the self, partners and others in the coming of death

B: Lay carer

- changing relationships means a new way of being for the lay carer who also has to plan for a future without their partner

C: Professional Carer

- there seems little awareness of the effects of MND on the sense of self and therefore changing relationship between the spouses

- psychotherapy or marriage counselling agencies may be supportive for engaging with sense of their changing selves and hence their changing relationships

6.9. DYNAMIC NORMALITY

This major category encapsulates five individual contributions concerned with re-establishing a sense of normality. It can be aligned to the need for 'homeostasis' in order to re-group, take stock, and try to live some life as well as witnessing its demise.

MND1 False normality
MND2 Re-establishing a normality
MND3 Pretence of normality
MND4 Need for a normality
MND6 Struggle for normality

Faced with a terminal disability, the previous 'life of normality' is lost, personal hopes and future plans are eroded, everything about one's life is sharply focused and an anticipatory fear becomes part of the new way of being, one's new normality. Coping with anticipatory fear demands adaptation to the physical and emotional challenges which presents a struggle for a new normality. Each new normality is transient however, as the process is not static, hence its dynamic nature.

MND3 continued going to work even through he had to be taken, arrive in a wheelchair, use computer technology to communicate in his work and only work 3 hours a day. Within these constraints he believed himself to be 'normal' but at the same time realised he was not;

'I'm trying to pretend that I'm alright, a marathon man...I'm having to really think that I'm alright but I'm not. I pretend that I am still normal...It's not really, is it? But in my mind I can still feel I am doing what I was before' (MND3)

Additional strategies to create a normality were suspending the disease and its implications so that you 'ignore it between you, to try to keep things going normally'(MND6) or through returning to the life before the disease by trying; 'to look as I always did, neat and tidy. That the house looks cared for. Keep up with the post, not so easy with one finger typing and an arm that gets tired. To be interesting through the light writer when people come to visit. To contact my mother and check on her well-being.... Everything the same but not the same but trying to keep the same' (MND6)

An example of the 'dynamic' nature of this normality is through realisation of significant turning points in the disease when adaptation is the key, 'I got up one morning, I managed to get into the bathroom, I tried to get on (the weighing scales), I got on with the right foot but with the left one I couldn't .. I could feel it going again and I said (to my husband) , 'You'd better come in here and bring my wheelchair' (MND5). This turning point in the disease meant her mobility shifted from independence to dependence. The effects of the disease is always progressive which is why the adaptation to a new normality is dynamic, 'I picked the teapot up the other day with my left hand to empty it and I nearly dropped it but that hadn't happened before, you notice things that are not quite what they were and then you get used to that and then it goes a bit further' (MND2).

6.9.1. Implications of category 'Dynamic normality'

The sense of the normal seems to fill a need for emotional rest from the traumas of reality, to replenish reserves for dealing with the anticipatory fear of the future. Although there are no remissions in MND, there can be weeks of stability when some strands of normality can be gained. Normality strategies can be activated before further deterioration and the search for a further sense of the 'normal'.

Practical implications

A: Cared For
- a sense of the 'normal' is related to familiarity to the situation and perhaps an element of feeling slightly in control again
- to help promote a sense of the normal, avoidance of crisis would be supportive
- maintenance of personal routine and when necessary the speedily development of a modified routine

B: Lay Carers
- awareness of need for a sense of the normal is important
- creating a sense of the normal can only be achieved with the co-operation of the lay carers and family
- close co-operation with their partners and the professional carers to discuss actual and potential problems should support this finding

C: Professional Carers
- recognition of this need should support its development
- interventions to support a feeling of safety and relief from immediate danger could be promoted to support this category finding.

- predicting changes in the person's condition should avoid periods of crisis (early feeding tubes, supply of essential equipment) and promote an early return to a sense of normality

Philosophical implications

A: Cared For
- being 'normal' is valued for its sense of stability, reduction of fear and continuance of life and therefore helpful for a sense of well-being
- as bodily changes occur, the attitudes of others should accommodate such changes rather than look shocked

B: Lay Carers
- promotion of a sense of control for the cared for may support the development of being normal
- knowing the new normal and adapting with it is essential

C: Professional Carers
- a calm, confident approach to the family with a measure should assist in this need
- as bodily changes occur, the attitudes others should accommodate such changes rather than look shocked
- promotion of a sense of control for the cared for may support the development of being normal
- knowing the new normal and adapting with it is essential

6.10. STRENGTHS AND LIMITATIONS OF RECEIVED CARE

From the starting point of their 'existential shock', and subsequent involvement with care professionals, the MND participants developed their own conclusions about receiving care. This category encapsulates their ideas of 'strengths and limitations of received care'. The strengths are identified as three main sections; functional interventions, demeanour and qualities of carers, situated friendship. The limitations are lack of continuity of carer and lack of emotional care.

MND 1/4/5/6 Limitations of others help
MND 2 Knowing others for support
MND 3 Knowing others for support
MND 5 Need for others
MND 5 Identification of criteria for 'good carers'
MND 6 Criteria needed for caring

Strengths of received professional care; functional interventions

People with MND received functional interventions from a range of care professionals. Each professional had their own distinct area of intervention which the MND participants referred to as the appropriate 'part specialist'.

In terms of maintaining hygiene and promoting mobility a MND participant states, an occupational therapist, 'came to my house, she thought I might use one (shower) to help me'.....'she (physiotherapist) gave me a frame and she said to me, 'Try all these exercises and things ..stop me getting stiff hopefully, stretching exercises' (MND4). These functional interventions were well appreciated by the cared for as they succeeded in making their lives easier, 'I've got an OT and he arranged for me to have a perching stool and a walking trolley so I could still be independent and do things in doors' (MND5).

The range of professionals involved with MND participants accumulated over time, each offering their own area of expertise. There could be up to nine disciplines involved but without co-ordination or continuity, 'I've had two people helping me with my exercises' (MND2) which was not well received.

Demeanour and qualities of professional carers

Practical help was essential but the demeanour of carers was pivotal for a positive reception of care. When talking about her district nurses, MND2 states, 'You can mention things and they said, 'Oh well, we can help you with this and we can help you with that'. I found sleeping difficult and they managed to get a mattress for me. They come in and they pick up on things and say, 'Oh, but we can help you with that ... they are both very good and Meg is so open and chatty and I do feel that I need to ask her I can, not bite my tongue ... they're friendly and chatty and so encourage you to talk (MND2).

It was particularly valued when they 'get to know you as a person not patient number 4' (MND6). MND6 wrote out an information pack for her carers, welcoming them to her home, confirming that her intellect was intact even though her speech was problematic and how her right arm was rather sore and tender. She reported that if the professional carers interacted with her as a person she got on fine but if not she 'went into her shell'(MND6) as she found the relationship inadequate and did not want to continue. The importance of being valued as a human being was strengthened by both parties 'knowing' each other. This meant developing a relationship and knowing the carer as if offered a sense of 'reliability, to feel safe and secure and to have someone dependable' (MND6).

Qualities they preferred in a carer which promoted relationships to grow included the professional keeping the focus on the patients, being able to listen, being cheerful and competent as well as functionally adequate.

'I'd want to be able to talk to them, someone I could talk to and when I say something I'd like them to take note of it... I wouldn't want them to keep talking about their own problems.. be cheerful, that's the main thing.... it's someone who knows what they're doing as well' (MND5)

'being a but cheerful, trying to keep people happy and doing whatever is necessary, trying to tell people what they are doing' (MND1)

The expert who makes caring look easy and does not consider the patient a nuisance was the approach favoured and summarised by two participants, 'somebody who's not really looking as if they are trying but really are doing things for you' (MMD4) with 'that feeling of confidence in what they are doing is very important' (MND1)

The cared for wanted to trust their professional carers. They engaged in a steep 'knowing curve' with these people and needed an immediate rapport. The listening skills of the carers needed to be acute, 'I think they ought to listen, know how to listen especially when there is difficulty with speech because you want to tell people things about you' (MND1). The presence of such a professional was supportive as, 'when you are on your own you think about it but when people are here you have to keep doing things' (MND6) and on these occasions action masked thinking about their reality.

Situated friendship

Situated friendship encapsulates the positive relationship desired and sometimes experienced by patients with their professional carers. It is 'situated' as they met through MND and it is their focus. Within this situation of crisis, they came to know each other as 'friends'. Continuity of professionals engendered a situated friendship and was identified as the desired way to receive care.

MND2 states her range of carers 'soon become friends' and how this personal investment from both parties maintained a sense of being valued for herself and was actualised in how they behaved towards her, 'They're not pushy, they're very aware that they're in your home, they want to do things how you would like them to be done, they're talking about their families and they include you, they're interested in my family, they comment on how I look or, 'Oh, you look tired today', I feel I can talk to them and as I say, they're becoming great friends' (MND2).

Actualisation of a 'situated friendship' was a great strength to the cared for. It gave them a sense of being valued as an individual and promoted a sense of safety with their carers. Although there was caring 'work' to be achieved, the relationship steered the way of being with each other. The notion of a 'situated friendship' was also extended to social carers and allowed them to relax together after the 'work' was completed, 'we joke, she's quiet and the type of person that likes the job, she's a caring person, whereas the other one wasn't... she washes me in the morning, gets me up, gets me in the wheelchair, takes me to the bathroom where I clean my teeth and then we sit down and have a cup of tea'(MND5).

Continuity was the key for this positive receipt of care as it permitted a relationship of knowing rather than being a receiver of functional interventions, 'they're coming in regularly they begin to know how I think, how I tick and how the family ticks and so they know the questions to ask and I've learnt to trust them and tell them truthfully if there are problems, if I can't cope with anything, if I'm fed up or miserable. I tell them and it gets off my chest and then they find out and it helps me to cope' (MND2). This relationship is certainly perceived and experienced as a strength by the cared for and can be seen as a 'possibility' in caring in terms of how caring relationships ought to be constructed in these potential long-term situations. These relationships highlight the need for others in extreme situations as 'it is better than struggling by yourself' (MND5)

Limitations of received professional care; lack of continuity of carers

The importance of continuity of professional and social carers cannot be understated. Any relationship issue became a non-starter if the constancy of interaction was not maintained or if the carer appeared in a hurry to leave. As 'it's someone who has frequent contact with you rather than someone who just shoots in and out' (MND6) that is valued.

Lack of emotional care

Unfortunately, not all MND participants enjoyed a 'situated friendship', a positive relationship or indeed any sense of relationship with professional carers. In these situations, functional interventions would be delivered but emotionally there were deficits in receipt of care. One participant who was asked which professional offered most emotional support replied, 'nobody' (MND4). The need was real however as another stated 'you're screaming, you're screaming inside' (MND6) and desperate to talk about the personal effects of MND not just the functional problems. MND5 developed her own strategy to keep people visiting was to 'always try to keep cheerful, cos nobody want to come and hear a moaner' (MND5). Those who could not follow this route admitted 'You're on you own a bit more' (MND1). The reported psychological limitations of care delivery highlights an important care gap for the MND participants. As although,' on the whole, they've been very supportive and kind but mostly people are frightened and detached. There's not many people who want to be involved personally' (MND3).

Particular negative examples of professional interactions were the consultants and their approach to confirming the diagnosis (reported in 'existential shock'). The importance of being treated as an individual with feelings and responses was highly valued by the MND participants. Insensitivity from one consultant continued after the diagnosis was told. When asked by a patient how death may present itself he relates, 'I suppose it's perhaps a bit difficult for him but I mean that's their business and they are in the business of telling people, I suppose they ought to know about you really, he was a little bit hard. He had a little fiddle a and rock in his chair and he said, 'Well, in the end you will have a sort of pneumonia, and then die of respiratory problems'(MND1).

These experiences of being treated without sensitivity are reported as exclusive to the consultants. Many MND participants stated their response was to stop attending out-patients with these particular consultants. However, one patient was referred to another neurological consultant in the same hospital. He had a more sensitive, valuing approach to both him and his wife through showing an interest in their perspectives and feelings. The patient resumed his appointments.

6.10.1. Implications of category 'Strengths and limitations of received care'

In terms of receiving functional help, this seems to be forthcoming and competently executed by the care professionals. If continuity of care is possible, this promotes knowing between carer and cared for which is desired. Such 'knowing' then allows the development of a 'situated friendship' whereby the focus remains on the patient and care is received from a person with an interested demeanour with qualities of listening and being cheerful. Care delivered from a position of strength therefore requires two ways of professional knowing: knowing their functional role and the patient as a person.

A combination of the two ways of knowing reduces limitations in care and extends possibilities. However, the most significant barrier for professionals to actualise the situated friendship approach appears to be the neglect of knowing the patient as a person coupled with no desire to engage with the suffering of these patients.

Practical implications

A: Cared For

- practical interventions through functional support are valued for promoting independence or offering supportive measures
- continuity of professional personnel is a strength as it offers the opportunity for 'knowing' between carer and cared for
- qualities of a professional care competence, active listening and attentive skills. cheerfulness, trustworthy, an instiller of confidence, a sense of being involved
- limited emotional support from professionals can leave the cared for with no emotional care

B: Lay Carers

- practical functional interventions also assists lay carers in their activities

- continuity of professional carers would allow lay carers to develop a relationship with them

C: Professional Carers

- functional care is judged satisfactory by the cared for but could be rather fragmented
- continuity of personnel is important, particularly as time is often short for the professional carers in their visits
- the amount of emotional support is perceived as minimal which may mean a counsellor or psychotherapy professional is required to help people with MND

Philosophical implications

A: Cared For

- knowing one another in a caring relationship is a vital ingredient of feeling cared for, it instils confidence and trust.
- a sense of worth and being valuing is promoting by receiving active and attentive listening
- the cared for identify how Being and doing need to inform each other in human interactions
- suffering and loneliness are not addressed by an explicit care professional and expose a value that is unattended in receipt of care

B: Lay Carers

- knowing the professional carers may also enhance their feeling of worth in the caring situation

C: Professional Carers

- as suffering and loneliness are not addressed by an explicit care professional, it begs the question of 'can holistic care be possible from the current organisation and role function of care professionals?'
- knowing patients requires a level of involvement with the focus always remaining with the patient - 'situated friendship'
- professionals need support themselves to offer such relationships to their clients
- question as to whether professional carers want to go this far in a relationship

6.11. REALITY UNMASKED THROUGH REFLECTION

The MND participants suggested that talking about and reflecting on their situation unmasked their reality. As the researcher, I was in a privileged position as a listener, for them to reflect on their lives in the world of caring and to give 'voice' to their experiences. Although the guided conversations were not intended as therapeutic outlets, the majority of participants expressed such appreciation. It was received as an emotional interest and support, which links to the previous category, where they highlight a deficit in emotional support and personal interest.

MND1 Talking promotes reflection and reflexivity
MND2 Reflection clarifies situation
MND3 Useful exercise
MND4 Reflection exposes reality
MND5 Reflection promotes thought
MND6 Reflection raises awareness

There was the shared belief that talking about their situations with a relative 'stranger' prompted reflection and a clarification of perspective. Some found this helpful whereas others did not. MND1 shared that it 'made you think how other people may be seeing you'. This surprised him as he had become so engrossed in his own world he had almost discounted any other. Clarity of thought was another outcome, 'it makes things clearer in my own mind, what I think about and how I'm going to cope with it and sometimes you can go on and on but if you talk about it, it defines things' (MND2). This stance was coherent with MND6 who stated the conversations 'put things in perspective'.

One participant did not wish for the reality to be defined at all. MND 4 declined meeting with me for the second conversation and even in the first stated, 'talking about it makes it much harder...I think it's not for me' (MNN4).

Participating in the research had specific significance to two participants in that they felt they were contributing to help others in the future. This was reflected in such comments as; 'I'm just glad there are people like you doing something' (MND1) and, 'I'd like you to get all the information you can' (MND2).

6.11.1. Implications of category 'Reality unmasked through reflection'

Talking to a 'stranger' about their experiences with MND was viewed positively with only one participant finding the experience too painful. The positive aspects were related to gaining clarity of thought, being listened to and having the chance to explore their experiences of MND, being cared for and feeling they were contributing to the advancement of understanding about MND. The implications are only considered from the view of the cared for in this category as it is a personal perspective. However, the lay and professional carers had similar attributes in terms of reflection, where it supported the majority but the minority found it too uncomfortable.

Practical implications

Cared For

- talking about their experience can assist in clarity of thought
- talking about their experiences can be distressing and should be stopped if this is the case
- using strangers reduces their responsibility of affecting someone else with their problems
- awareness of the effects of talking about their situation may be unknown to the participants before beginning

Philosophical implications

- sharing the burden of 'being- in-extremis' with another can lighten the burden
- finding ways of being not realised before discussion can be positive or negative
- offering a vehicle of talking about their experience confirms their sense of being and making a contribution to others

APPENDIX 12

EVIDENCE SUPPORTIVE TO LC GROUP CATEGORY FINDINGS

This evidence is supportive to the findings presented in chapter 7. It is sequenced in accordance with chapter 7 (i.e. section 7.4., 7.4.1. etc) to facilitate orientation.

7.4. FORCED LIFE CHANGES IN CARING FOR ANOTHER

All six participants experienced 'forced life changes' resulting from their partners' disease. Role changes are central to this category. Lay carers had to abandon their own leisure pursuits, learn new skills, take on new responsibilities and often do the work of two people. Some changes were embraced, others were considered onerous but all were forced through the effects of MND. The contributing individual categories agreed on the loss of personal freedom, realisation of the burden of lay caring and recognition that caring for another with MND was a full time job.

LC1 Response to forced life changes to lifestyle
LC2 Loss of own life
LC3 Life changes
LC4 Forced restrictions
LC5 Forced personal losses
LC6 Forced changes on carer

The responsibilities of caring made them feel trapped which was challenging to their patience, 'we cannot escape really, it's always there ... if you are with a person who is ill, it's always at the back of your mind that he is ill and you have to work with it everyday, it's always there' (LC1). The feeling of being trapped was also experienced by people with MND so together they had 'to accept that you just cannot do things that you want to do' (LC5). The demands of the disease took over both of their lives.

The continuous nature of caring and the resultant responsibility made carers describe it as 'dammed hard work to start with and it's taken up practically my whole life now, I mean when you retire you don't expect to get anything like this' (LC2).This pressurised experience led to some irritation, 'You can care for a person for a day but it's not the same because you know that the next day you are going to be free... I'm very impatient sometimes. I get very annoyed with him sometimes ....I would like to go to the concert or I would like to go to the theatre' (LC1). The burdensome aspect led 'to a point where it's not just a routine but a chore of having to get up and do all these things' (LC5). The need for respite interventions was clear but not always possible or sought as there was a sense of pride and duty involved.

The practical caring demands of helping their partner remain comfortable and assisting with mobility continues throughout the 24 hour day with the greatest pressure experienced as night interruptions;

'once I've done putting her to bed, then she wants to get out and go to the toilet and that's a BIG thing to do. I've got to get her out of the bed, I've got to lift her legs out, I've got to get the strap and I've got to lift her up off the bed onto a chair, take her up to the toilet, do the same out there, bring her back and put her back in the bed, settle her down, you know?' (LC2).

When described in this detail one can almost feel the physical effort and sleep deprivation that the lay carer is experiencing.

Apart from the intense physical caring activities there was the household to maintain. This was particularly challenging for the men, 'you've got to do a lot of thinking ahead, it calls on mental and physical awareness of what the problems are' (LC5)... 'I had to learn how to cook, I'd never cooked in my life, I had to arrange to get all the food, as regarding new clothes, I mean, some of it I had to go out and buy for her, some of it was wrong, I had to take it back and get a different size and things like that' (LC5). These experiences made them realise that being a lay carer to a disabled partner is very much a full time job, as one lay carer explains, 'Just before all this happened I was looking for a full time job and now I feel this is it' (LC3).

The shifting roles ultimately developed into lifestyle changes. LC1 had to take early retirement from a senior teaching role, LC6 had to reduce his working week from 5 to 3 days away. Spending two days at home meant losing promotional prospects. LC2 always had to be in the house to attend to his wife whereas before he was always out doing D-I-Y for neighbours and themselves. Forced lifestyle changes also meant not being able to go for walks together, going out shopping or on holiday together. The lay carers were consistent that 'it's altered my life' (LC2) almost beyond recognition.

The forced changes were not only practical as emotional changes were also apparent. LC3 recalled her lost dreams, 'It's a kind of sadness. I remember saying you've got this picture of yourself walking off hand in hand into the sunset and that's just kind of gone' (LC3). The sadness never went but she learnt to, 'suppress unhappiness, the sadness of the situation [and if] you've got to get on with it and live your life anyway so it's kind of kept down as it were' (LC3). Some of the forced changes were seen as positive gains, such as developing new skills, 'when I feel about achieving things like driving the car I feel I've more confidence in myself and sometimes proving to myself that I can cope with the situation I'm becoming more confident and assertive' (LC3). This change for her was seen almost as a sliver lining to an impossible situation.

In contrast, the transition from spouse to carer was felt acutely negative, 'I think I am more like a nurse and not a wife anymore' (LC1). Her husband 's speech had deteriorated very badly and although he was still walking, she was finding it increasingly difficult to communicate with him. She had begun to close down her relationship with him to the extent that 'I just go upstairs now and I don't say anything. I just go upstairs' (LC1). This perspective of shifting role from wife to nurse devastated this woman. It also annoyed her to the extent that she became annoyed with her husband and withdrew from him.

Forced role changes were seen in both partners; as one had their physical abilities compromised, the other had more responsibilities and work. Almost like a see-saw, the burden on one created a forced imbalance on the other. As the person with MND became less out-going because of speech difficulties and sadness, the lay carer reported being more irritable, more tired and more socially isolated.

7.4.1. Implications of category 'Forced life changes in caring for another'

A change of circumstances in one partner creates a change in the other. The extent of that change is almost a correlation; as the person with MND deteriorates, the responsibilities of their partner increases. There were some outcomes in terms of learning new skills and developing personal confidence but more frequently the experience was of never-ending hard work, resulting in exhaustion.

Practical implications

A: Lay Carers

- an increase in responsibilities meant that there was less time for themselves
- caring is viewed as a full time job, worse at night.
- outside practical help was required, particularly at night, but reluctantly sought
- additional roles and responsibilities may stretch the resources of a lay carer beyond their physical and emotional capabilities

B: Cared For

- awareness of the exertions and pressures on their lay carers may encourage them to be receptive to external help/respite interventions
- although the cared for do not wish to relinquish all roles and responsibilities, negotiation with their lay carers may help identify which roles and responsibilities they could maintain to help themselves and relieve their lay carers
- guilt may develop in the cared for as they see the extra effort their partners are having to invest

C: Professional Carers

- awareness of the pivotal role of lay carers is vital and the stresses they endure in terms of physical, emotional and role change
- involvement of lay carers in decision-making is imperative, as without them the cared for may not be able to remain at home
- economic implications of hospitalisation are vast, so it is more cost effective to support a lay carer to continue in the home
- suggestions of respite care may be more welcomed if encouraged by a professional carer

Philosophical implications

A: Lay Carers

- their whole being is under stress; no time for themselves can lead to emotional and physical exhaustion. Their own needs may become subsumed and resentment develop
- reduction or removal of their hobbies and interests gives them a sense of loss of themselves as well as an anticipatory loss of their partner
- a change in the sense of self through a forced situation can result in internal tension
- the importance of voice: seeing their partners as non-communicators resulted in not seeing the person they knew

B: Cared for

- the basis of the original relationship affected their listening skills for each other
- appreciation of the effects of change might help them accommodate and develop new ways of being together

C: Professional Carers

- sensitivity to lay carers is necessary
- encouragement and emotional support is needed for lay carers
- listening to lay carers emotional stance would offer insight into their coping progress
- predicting emotional/physical exhaustion early and arranging respite might help prevent a crisis of being for lay carers

7.5. LEARNING THROUGH CARING

'I think caring is underestimated' (LC5) highlights a significant learning outcome based on the lay carers' accrued experiential knowledge. Lay carers had to learn both practical and emotional aspects of care which they all found challenging, 'I know what it's like now to have to care for someone. I just feel sorry for everybody who has to do it' (LC2). Learning to care involved learning problem solving skills, practical skills, harnessing personal and professional resources to care and developing skills of empathy. Not all lay carers were successful students, as although, 'Some can cope with it very well. I thought I could but I don't think so' (LC1).

LC1 No personal resources to care
LC2 Learning through doing
LC3 Using personal resources to care
LC4 Learning to care from professionals
LC5 Learning to think like the cared for
LC6 Learning care strategies

Drawing on personal resources to care, in many cases meant first locating such resources and then inevitably led to behavioural change. One participant with eighteen months experience in lay caring stated in the second guided conversation how, 'I feel more mature I suppose and I can cope more and more' (LC3). She had risen to the challenge of being a lay carer. It had changed her being from a full-time housewife to being the main carer and head of the household.

Lay carers realised that the extent of love for their partners influenced their caring ability as, 'if you like and love the person you're looking after it's so much easier than if you don't like them very much. If I didn't like my wife as much as I do, I don't know how I would cope with it' (LC4). Another lay carer phrased it thus; 'I feel clumsy at first, I feel well, I want to care for her, clearly to say she's my wife probably doesn't mean anything except she is the other half of my heart and therefore to look after her is important (LC6).

Trying to think what it must be like to have MND was an approach a lay carer learnt to guide her caring; 'I let him know I'm here and I'm here to help and support him. I try to share things as much as I can really. I try to come and think how I would feel. I mean I'm sure I wouldn't be able to cope half as well as he does but I do try to feel how he must feel really - not very nice. No' (LC3).

Learning selflessness, to think of the person with MND before oneself emerged in learning to care as you have to, 'think of the person you're caring for, not of yourself. You have to change your whole outlook on life. It's not what you want it's what the person cared for wants' (LC5). These were successful lay carers but others were not so willing or able to learn. LC1 admitted her reluctance to care and was further challenged when her husband's speech declined to the extent she gave up, 'I don't try anymore' (LC1). Her irritation of not understanding her husband left them without communication 'we do not turn to conversation any more' (LC1) which had been pivotal to their relationship. Her idea of being a person was strongly associated with the ability to communicate. It was not the loss of bodily functions that took away the uniqueness of being human but the loss of speech. This was experienced as loss of her spouse. Without communication she lost the person she knew,

'he used to, have] a dry sense of humour, very funny and now that has disappeared.. one year he was young [now he has] become very old, an old man.. He has become very old and it is very sudden and a change from the person, he has changed entirely' (LC1).

Being a person in this example seems to be related to expression through language and being able to reach another through this communication route. Once her partner lost these abilities she was unable to see him as he was and this blocked her ability to care. Another particular human attribute was attributed to hands, 'the disease attacks everything that is uniquely human about you, your voice, your hands' (LC6).He found his wife's loss of hand function an indication of losing the sense of being human.

Motivation to care seemed based on love, not a romantic effusive show of affection but a deeper more sustaining love that feels natural, 'I think the word 'carers' conjures up this kind of person overflowing with love and affection, you know, slippers at the ready and I think I'm not that sort of person….. I mean I care for him because I love him, so I just do it' (LC3.). Love motivates you 'to do your best…I have no call for doing any of this, I'm not necessarily very good at it but I try my best' (LC5). The notion of love seems stronger than duty. Inherent in love motivation is doing ones best through respecting autonomy, 'I don't try and say, 'Oh come on you ought to be doing more exercises' or 'Come on, the consultant told you to do this', but that's entirely up to her. I'll often say, 'Do you want a hand?' or 'Do you need any help doing that?' …. she is her own person and all her faculties are there and I'm not going to try and treat her like a child' (LC4).

An important strategy was learnt in coping with MND, 'the thing to do is, you must always remember with this dreadful disease, is to keep ahead of it, don't let it overtake you, that's the policy I've followed all the way through' (LC6). In this pursuit, problem-solving skills were particularly important for learning to care effectively, 'You've got to do a lot of thinking ahead, it calls on mental and physical awareness of what the problems are' (LC5). In his case he stated, 'I've learnt not to do any heavy lifting, you've got to use all the appliances' but unfortunately learnt this through trial and error and from gaining a bad back having repeatedly lifted his wife.

The practicalities of caring were responsive to the degree of disability. Being able 'to do' for their spouse was a source of comfort for the lay carers. Even LC1 describes how despite her lack of personal resources to care she learnt to massage her husband with aromatherapy oils to help him relax. She admitted that it is 'quite sort of pleasant to help someone in that way, really, to care for someone knowing he can relax. It is not hard at all. I'm glad I can help in that way' (LC1). She found a new communication medium. In contrast, the practicalities could be quite irritating, 'and then there's her pillow's got to be tucked up underneath her neck, she's always been like that so I have to mess around with that' (LC2).

Practical instruction was sought from professionals for lifting techniques to knowing how to gain equipment, 'we've a nurse in here but she showed me how to do lifting the best way, best angle to put a chair when lifting so you're not turning completely round, you only turn a third of a circle'(LC2). Another lay carer need help in getting his wife out of the car, 'whereas before I would have gone round and tried to haul Liz out, the physio said, 'No, just have a hug and stand up' and it was so easy when she's explained it' (LC4).

Much of the practicalities were to do with physical effort, 'I really have to do most things for Henry. I have to get him out of bed and I give him a bath in the morning and I shave him and wash his hair in the morning, then I get him dressed and give him his breakfast' (LC3). This quotation is one of many examples of the practical assistance they all had to encounter every day which drained their energy, time, patience and commitment.

Learning to be inventive was a common outcome. For instance, when swallowing became a problem one lay carer 'bought one of the Braun multi-mixers. My mother-in-law's got one and she showed it to me to help a bit with the meat as I think it's chewing the meat, he gets so tired chewing the meat' (LC3). The practicalities of caring, although difficult and tiring were also a silver lining as they gave the lay carers something to contribute and something to do. It seemed that the action of 'doing' permitted the diminution of 'thinking' about the enormity of outcome. The 'doing for' another 'takes me away from sitting around thinking how terrible this was' (LC4).

7.5.1. Implications of category 'Learning to care'

Caring for one's partner is motivated by love but requires learning new skills and ways of being. It is demanding, exhausting and requires not only physical resources but much investment of the emotional self. Learning empathy and selflessness was required in caring for a partner. Although professional carers offer practical help and guidance, problems were continuous. As their partners' physical deterioration progressed it often demanded further innovation to cope. Positive feedback from any experience re-motivated the lay carers.

Practical implications

A: Lay Carer

- caring is under-estimated
- practical caring for a disabled person demands practical help in many domains such as lifting and handling, nutritional advice
- learning to care is exhausting. Rest and relaxation should be built in to the timetable

- need for problem-solving skills to overcome particular situations related to activities of living
- need for professionals to educate lay carers in practical ways of caring

B: Cared For
- offering positive feedback to the lay carers may motivate them to learn and care more
- appreciating lay carers are learning and cannot solve all encountered problems

C: Professional Carer
- lay carers need to learn practical skills and can be helped to do so by the professionals
- questioning lay carers concerning their coping mechanisms and their needs is imperative to capture these learning needs.

Philosophical implications

A: Lay Carer
- learning to care requires love
- requires motivation, an open mind and the ability to ask for help
- a partner has emotional connotations and requires supportive strategies for adjustment of roles
- previous relationship bonds affect the caring dynamics
- ability to communicate with your partner affects the ways of seeing your partner as a person

B: Cared For
- caring is demanding and uses up many personal resources which may deplete the lay carers' reserves
- communication is vital to remain a person in the lay carers sense of being

C: Professional Carer
- need for awareness of the relationship bonds between lay carer and the cared to appreciate its potential course
- need to promote ways of communication between lay, cared for and professional to keep the focus on the person rather than the body

7.6. THE VULNERABILITY OF BEING A CARER

The forced life changes and learning to care have their costs. 'Vulnerability' captures the suffering and emotional distress experienced by the lay carers; 'This is horrible. It's worse than cancer' (LC2); 'I hate it. I hate it' (LC3). Social isolation, suffering, caring received from others and caring for selves are four elements of this category.

LC1 Distanced from others/Caring for self
LC2 Caring is hard work/Need for others to help
LC3 Suffering of the lay carer/Need for support in caring
LC4 Emotional vulnerability/Need for support in caring
LC5 Emotional caution/stress/Suffering demands care for the carer
LC6 Importance of hope and goals

Social isolation

As the cared for experienced feelings of isolation, the social network of the lay carers is reduced. Communication deficits was the main feature as one example illustrates; 'our neighbours recently said that I can't understand him and don't want to talk with him' (LC1). Dinner invitations and the friendship stopped. The visiting professional carers did not always attend regularly which enhanced this isolation and caused emotional stress, 'used to go weeks and sometimes months before I saw anybody, I mean the social worker was five or six weeks sometimes' (LC5).

Lay carer suffering

There was no evidence of any care professional being directly allocated to support the lay carer. However, the 'need for moral support' (LC5) was clearly identified as caring is 'damned hard work' (LC2). The hard work and responsibility was associated with what might happen if they became ill from caring with the realisation that, 'I don't think I could ever be ill now. I don't know what we'd do' (LC2). A clear distinction is made between the effects of caring on a lay relative and a paid carer, 'I'm suffering an emotional upset at the same time as caring, so as far as doing the job I'd just be me, ...I'm emotionally upset by it all so that's the added stress and stain, it's not just caring, it's suffering' (LC3).

Seeing the effects of MND everyday on their loved ones but knowing they cannot stop it took a tremendous emotional toll on them in addition to the physical energy they needed to care. Indeed the physical interventions at least allowed them to 'do' something whereas 'emotionally. That's the worst aspect for me' (LC3). They needed care for themselves in this aspect.

Others caring for them

They appreciated the personal strength they could gain through others which included a range of people from family members, volunteer groups, friends and care professionals.

Some care for the lay carers naturally came from their partners with MND. Trying to problem solve work loads and domestic arrangements they could negotiate possibilities. The majority of lay carers clarified how their practical and emotional caring was reciprocated by the people with MND. MND partners would tell their spouse to get their hair cut or change a badly chosen tie or not to bath them tonight if they looked tired. The caring was two-way but with different manifestations. One lay carer illustrates this, 'I don't view myself as a carer, it's just a partnership where one partner isn't able to do as much as they used to be able to do in the partnership, ability I mean. Liz can still encourage me and talk to me whatever but I've got that luckily, I don't know what I would do if she lost her faculties' (LC4). Her speech was impaired but they managed to understand each other.

Friends could be a helpful source of support; 'I've got a couple of school friends and they've been quite good and I've been out for a couple of evenings with them just having chat' (LC3). Some friends could alleviate some of the intense responsibility and offer some free time to the lay carer, 'if someone comes in and sits with her it gives me a chance to slide out into the garden' (LC2).

Carers recognised the need for social carers, particularly when their spouse was requiring assistance throughout the night, 'what we have asked for is someone to sit with Henry one night a week to help him turn at night because I'm getting tired' (LC3). However, gaining such relief was difficult and often came too late.

When care professionals took time to listen and talk to lay carers, this was appreciated. It demonstrated that lay carers were considered in the equation with needs themselves. In addition, if lay carers witnessed a good rapport between their partners and the professionals, this offered a sense of being cared for overall, 'I think the way she is, especially when Henry talks to her, she says things like, 'That's exactly how I'd feel' and things like that, she kind of knows, the feeling that she does actually think what it might be like' (LC3).

However, the number of people engaged in caring for one person can be large (for example: in the case of MND3, up to nine professionals and two social carers as well as wife, eldest child and other family members). The need for team work was considered essential. One lay carer stated it is 'a team effort... the social worker has pulled together a team and I think she's gone out on a limb with her boss and made sure Pam has everything' (LC6). Certainly in this study, when a professional team was organised with a co-ordinator, the client and lay carer's experience was reported far more positively those without such a system. Their care was more haphazard (see also category entitled: strengths and limitations of health professionals). If a professional care team was organised, then both cared for and lay carer were able to develop a sense of stability with their carers, to get to know and feel relaxed with them, each came to know the other and their ways.

Lay carers were receptive to the help extended by the MNDA, voluntary organisation. Although two did not attend the meetings (one did not want to witness people other deteriorate and another could not organise transport due to mobility problems), they all talked highly of the knowledge and experience the voluntary members possessed as, 'she suffered the same thing with her husband so these people know' (LC5). Having a person to contact over above the social and health care professionals was viewed as a very supportive, 'If I've any doubts .. I talk to Judith' (MNDA voluntary visitor) (LC6). Ideas could be exchanged in terms of practical support, emotions could be shared between those who had lived the experience and equipment could be borrowed.

Caring for selves

Two ways of caring for themselves were illustrated. One lay carer talked about his coping strategy which was 'to have something to look forward to' (LC6). With his logic he knew a cure was not possible but how, 'the concept of hope is always there, there is the hope that it [MND] will have a remission' (LC6.).A different approach was self-praise. LC3 was able to consider her achievements as, 'physically it's quite difficult, the feeling you get is proportionate to it's difficulty isn't it? If something's difficult then you think, 'Well, that's good, I did manage that well'' (LC3).

7.6.1. Implications of category, 'Vulnerability of being a carer'

The hard work, emotional and physical involvement soon led the lay carers to realise they were suffering as well as their partners. They experienced social isolation and vulnerability but managed to find support from friends, family, professional and voluntary carers and not least the cared for themselves.

Practical implications

A: Lay Carers

- caring is hard work, physically and emotionally demanding
- social isolation is heightened as their partner's communication ability declines
- physical and emotional suffering is experienced
- lay carers need help in terms of physical assistance combined with moral support
- MNDA members can offer experiential knowledge for lay carers
- co-ordination of professional carers was a supportive strategy for lay carers

B: Cared For

- realisation that caring is demanding of their partner may help them be supportive in return
- the need to accept care from others is important to be supportive to their partner
- the need to remain understood is crucial in maintaining relationships with people

C: Professional Carers

- awareness of potential suffering lay carers endure is vital so they can look for signs of distress and present alternative strategies
- particular attention should be offered to lay carers in terms of their own health and safety in being a carer
- maintaining communication channels between the cared for and others is vital for success
- lay carers are pivotal and should be nurtured
- the need for regular attendance on clients is clear to reduce their social isolation

Philosophical implications

A: Lay Carers

- social isolation is a precursor to suffering as it promotes a sense of abandonment and being alone in the face of adversity
- receiving care from others needs to be accepted and actively pursued to balance their emotional stress
- strategies to care for self require a sense of self-importance which can be diminished when caring for another

B: Cared For

- caring for their lay carer is well received but needs promotion to redress the balance of the relationship
- appreciation that lay carers are suffering as well as the care for stimulates the need for external support

C: Professional Carers

- professionals need to engage with lay carers to appreciate their vulnerability
- awareness of the social isolation and personal suffering of the lay carers may encourage greater understanding of the effects of their caring and promote professional support
- professionals need support in caring and in this area they may relate to the lay carer; inter-professional co-operation is one positive approach for this

7.7. TEMPORAL REALISATIONS

The concept of time is bought sharply into focus for the lay carers. Two dimensions emerge; first the limited amount of time they have left with their spouse and second how the speed of the disease highlights the immediacy of need in relation to receiving equipment and help.

One lay carer describes how his new perception of time is central to his existence which is 'a bit like being on a sledge with the wolves chasing in that however fast they move the anxiety and threat of her future remains'. (LC6). Another talks of the effects of limited time in how 'I think that time is very precious as well, I don't like to waste time' (LC4) and how he has become, 'less tolerant of time wasted, that which is out of my control' such as waiting for appointments and people to visit who do not turn up at the agreed time. Time becomes a pressure in that every minute needs a purpose and needs to capture a memory. Operating 'day to day is a very good strategy' (LC6), an approach adopted by most of the lay carers and the cared for.

Caring for someone 'takes up a lot of time' (LC6) which links to their loss of personal time and perception of caring as a full time job. The temporal pressure also affected their occupations and balancing of responsibilities, 'it has affected my work concentration and the actual time I can devote because I know I have to be back home at certain times when the child- minder or nanny leaves' (LC4).

LC1 Timing of help
LC3 Temporal shifts
LC4 Temporal pressure
LC5 Temporal concerns
LC6 Centrality of time

The time limitation with their partners focused them to prioritise time. Lay carers did not look too far ahead because it was a future of uncertainty tainted with an assured physical deterioration for their spouse. During the first conversation with LC3 that future was 'looking a bit ahead but I don't tend to look too far ahead because I just deal with each day at a time' although on the second conversation when they were more experienced in dealing with the uncertainties, 'I still can't think of the future. I don't really think about next week until Sunday evening. It's almost a week at a time. Henry, I think, is the same' (LC3).The shift from taking day to day had extended to week to week.

Lay carers quickly realised the importance of requiring special equipment at specific times in the disease trajectory. Most commonly, equipment took too long to arrive and was therefore too late to be beneficial;

'everything was too late, everything you require takes time. I mean the hoist took a fortnight to come, during that fortnight I still had to lift her in and out of bed. These items should be made available almost immediately, it's no good a fortnight later. I mean the wheelchair was five weeks coming' (LC5).

However, the opposite also happened when equipment was offered too early; 'I feel that perhaps some others can need the chair when Henry still does not need it. Perhaps we don't want it at the moment but will want it in a months time' (LC1). These two opposite experiences highlight the importance of timing when caring for people with MND.

Lay carers reported how the professionals were always short of time; 'they never really had time. They were quickly in and quickly out.... I think they give as best a service as they can under what must be terrible conditions because they're flitting from here to there dealing with so many. There's just not enough nurses to go round' (LC5). The majority of lay carers had no professional co-ordinator of care which led to the realisation that, 'There's no organisation. Everyone comes at the same time' (LC1). This led to frustration for the lay carers.

7.7.1. Implications of category 'Temporal realisations'

Time became a central focus as lay carers knew it was limited for their continuing partnership but also was central to managing care, help and equipment. The limitations of professional time was experienced.

Practical Implications

A: Lay Carers

- time is precious and needs to be spent wisely
- it is not possible to look too far ahead but a balance needs to be gained with planning

- lack of organisation of professional carers creates more problems
- equipment needs should be continually assessed to get the timing right

B: Cared For
- time is precious and needs to be spent wisely
- it is not possible to look too far ahead but a balance needs to be gained with planning
- if equipment can be organised appropriately it increases the chance of a greater quality of life
- lack of organisation of professional carers is not conducive to temporal planning

C: Professional Carers
- the need for equipment stores and professional access is made clear
- the need for regular accurate assessment of client need is clear
- there is a need for a professional carer to co-ordinating services through a team approach .
- regular attendance at a home situation is vital

Philosophical implications

A: Lay Carers
- time is the essence of life and needs to be used wisely
- time cannot be bargained with, it runs its own course
- the finite nature of time is sharply realised in this context

B: Cared For
- the shortness and importance of time is shared between partners

C: Professional Carers
- need for sensitively and awareness of the time pressures on lay carers
- need for appreciation that lay carers experience time in two dimensions; time left with their partner and the timing of help

7.8. THE FALSE NORMALITY

Lay carers had had their sense of routine removed but tried to establish new routines as the situation demanded, ‘Having a routine keeps things ticking for me’ (LC2), which served to hide the reality. This new routine however usually revolved around the needs of the cared for as, ‘my life revolves around Henry’s life now’ (LC3) which was her new normality. A sense of stability permits ‘normal’ life to continue, although lay carers knew that their attempts for a new normality actually created a false normality

LC2 Normality before reality
LC3 Re-creating a normality
LC4 Striving to maintain normality
LC6 Denial of reality

The following detailed story offers insight into the demands of caring which become a 'false normality';

'naturally I've got the same routine.. in the morning when we get up I usually go out and put the kettle on for a cup of tea... She doesn't like stopping in bed because of the aches. I take her to the toilet first then I keep her in the chair while I do her breakfast .... I go in and have a shower and shave and get dressed and then I take her in there. She can't bath because we are waiting for the bath lift....' (LC2). Apart from the action routine LC2 did not talk about MND or the bleak future, instead acted 'as if we're just normal, you know' (LC2). He adds a further example, 'I've told her before, try not to cry ... at the wedding we went to it was never mentioned. She had a good time and nobody mentioned it' (LC2). His wife was the patient who initially agreed to join the research but once we started she withdrew. She burst into tears and sobbed. My interpretation of this event was her husband's influence over her which had prevented her from being able to address her feelings when the situation arose. However, I was unable to confirm or validate this interpretation.

Another carer describes their normality attempts at mealtimes, 'we do all try and sit down together' (LC3) although her husband was being partially tube fed. The importance of this was 'for everyone really. It's for the children and us and also a kind of feeling that we're not going to let it spoil everything' (LC3).

LC4 and 6, try to continue life with outings and pleasure without talking about MND all the time as 'the aim [is] to have something to look forward to all the time' (LC6). LC4 tries 'to address her needs as they arise' as they would approach any problem they encounted in their lives with the aim of 'trying to make life as normal, I don't know if that's the right word but comfortable and pleasant during that time' (LC4).

7.8.1. Implications of category 'The False Normality'

One way of coping with a distressing situation was to create a sense of the normal within the abnormal . Although this could not avoid practical issues it did offer a strategy for not confronting their situation to allow relief from the acuteness of the tensions and pressures.

Practical implications

A: Lay Carers
- creating normality when it does not exist allowed the lay carers to cope with day to day practical issues

B: Cared For
- the cared for also strove for a sense of the normal, being compatible with the lay carers

C: Professional Carers
- professionals need to be aware of the need for a level of normality even in extreme situation.
- planning visits would facilitate 'fitting in' with the routines established by the families

Philosophical implications

A: Lay Carers
- a sense of normality, although false, offers a sense of coping
- normality allows a person to adapt to extreme situations
- normality allows emotional angst to be rested

B: Cared For
- a sense of normality, although false, offers a sense of coping
- normality allows a person to adapt to extreme situations
- normality allows emotional angst to be rested

C: Professional Carers
- professionals need to be aware and supportive of the need for a sense of normality

7.9. STRENGTHS AND LIMITATIONS OF PROFESSIONALS

All six lay carers experienced strengths and limitations of care professionals.

LC1 Strengths and limitations of professionals
LC2 Strengths and limitations of professionals
LC3 Support from professionals
LC4 Supportive professional interventions
LC5 Need professionals
LC6 Caring needs teamwork

Strengths in functional skills

The lay carers were generally satisfied with their interactions with the professionals in terms of their demeanours and skills, 'we went to see the physiotherapist at the hospital. He was very pleasant. He helped by saying, 'Well, we can get you this or we can help if he needs that', it is a kind of feeling that you have someone around you who could help if you need something, you can always refer to them' (LC1).

LC2 had great praise for the occupational therapists, 'she's very cheerful, very good. She rang up yesterday and told us she's got a cushion for us. That's going to make a hell of a lot of difference to my wife sitting down, you know, because it hurts her in the car, it hurts her in the chair. She's also getting us a bath lift that's run on a compressor.. she comes pretty regular. I can't fault them in any way. I think they're marvellous' (LC2).

A strength noted by LC3 was how a professional interacted with her husband, 'she says things like, 'That's exactly how I'd feel' and things like that, she kind of knows, the feeling that she does actually think what it might be like' (LC3). The sense of involvement and understanding which this professional displayed was praised as offering a genuine involvement in their tragedy.

Limitations in inter-professional co-operation

Limitations were revealed as lack of professional co-operation in that 'we don't have any doubts about anybody professionally, it's just weaving it together for my wife, [which] clearly is the difficulty' (LC6). This lack of teamwork amongst the professionals was a common problem. There would often be an initial arrival of an army of care professionals visiting and assessing. The feeling of being overwhelmed by the many visiting professionals led one lay carer to state '[we] used to have half a dozen professional faces and I just couldn't place them all and I never knew which one to speak to' (LC4) which meant, 'I was getting frustrated with never knowing who to contact'.

Not knowing who to contact for a particular problem highlighted the confusion experienced by lay people of functional professional boundaries. Only in two cases out of the six (LC3 and LC4), was a co-ordinator identified to allocate appropriate professionals to specific problems. The LC/MND4 couple, in addition to having a named co-ordinator from social services, also opted for the self operating care scheme, whereby social services funded them directly to purchase their own services. They found this approach very helpful giving more control in co-ordinating helpers. LC/MND3 enjoyed the services of a team co-ordinator which made them feel more in control of their lives. The health needs of MND3 took priority over the social needs so a neurological nurse specialist was the designated team co-ordinator. This role usually fell to a social care professional but was negotiated on the basis of patient need.

In contrast, a lay carer who did not receive a co-ordinated approach felt marginalised by the care professionals suggesting, 'I think carers should be asked a lot more questions because they know the problems' (LC5). In his case a wheelchair was delivered but would fit the doorways. He felt his wife was not adequately assessed, she was not asked how she managed to go to the toilet or other personal details which he had to problem solve through trial and error. As well as receiving a poor service he complained of inadequate time to solve his problems as, 'they're here 20 minutes and then they're gone'.

Need for more emotional care

Lay carers reported a lack of emotional care received from professionals. One stated how professionals work in a detached manner. 'I think it's all talked about mainly in a business like manner rather than in an emotional way' (LC5). Some individuals were identified as being more interactive as 'she's ever so nice. Yes, she's really good. She helps Henry with exercises and also she's quite nice to talk to' (LC3). There was a definite need for care professionals to be good communicators with a caring attitude involving a genuine interest in the lay carer as well as the patient.

Two contrasting approaches by two consultants illustrate how clients respond to this aspect of caring. The incident led a lay carer and spouse to leave one consultant. Firstly the poor example, the lay carer recounts an attitude problem whilst telling the diagnosis, 'I think it was the way he said it, I think it was very unfair. I think he could have done it better. That's why we don't want to see him anymore' (LC2). Followed by the good example; 'he's so nice. I think it's the way he treats the patient, he's so delicate with them and he went all over her and checked her, he made sure she wasn't in pain anywhere, but the other chap, he couldn't care less'. The conclusion reached by the lay carer of the difference being, 'you see the different in the two doctors. It's his attitude' (LC2). Certain consultants were repeatedly and independently highlighted as belonging in either of these two categories. The lay carers independently agreed that they valued a professional who exhibited sensitive communication skills as well as a sound knowledge base.

As the disease progressed however, professional practical interventions reduced. This led lay carers to realise, 'there's not really much any of them can do is there?...I've got a speech therapist coming down here. I don't know what she'll do, mostly breathing exercises and things like that'(LC2). This was a hard lesson to learn, that ultimately the professionals could not 'do' any thing to change the course of events. However, in their withdrawal from functional care their visits stopped, the emotional care was not considered reason enough to visit.

7.9.2. Implications of category 'Strengths and limitations of professionals'

Lay carers needed and gained support from professionals but they also highlighted significant areas of deficits.

Practical implications

A: Lay Carers
- professional practical interventions and the supply of equipment for people with MND improved the lives of the lay carer
- lay carers appreciated professionals volunteering helpful solutions to difficulties and reassuring them
- a co-ordinated approach through a team mechanism was greatly valued

B: Cared For
- the support and limitations of professionals affects the lay carers

C: Professional Carers
- team work with a co-ordinator is supportive action for the lay carer
- prompt supply of equipment is seen as a strength
- need for accurate assessment, using listening skills and questioning about mobility and hygiene needs should be addresses to both cared for and carer
- time spent should be clear and unhurried, appointments made should be regular and kept even when functional interventions are reduced

Philosophical implications

A: Lay Carers
- lay carers need to experience from others a sense of genuine involvement in the tragedy
- empathy from professionals is received as caring
- Being is as important as knowing, if not more so
- a cheerful disposition was considered a positive attribute

B: Cared For
- clients need to experience from others a sense of genuine involvement in their tragedy
- empathy from professionals is received as caring

- Being is as important as knowing, if not more so
- a cheerful disposition was considered a positive attribute

C: Professional Carers

- Being is as important as knowing, if not more so
- offering a sense of genuine concern and involvement is received as caring
- visiting when there is no function interventions offers the message of emotional care

7.10. PREPARING FOR LOSS

Thinking about life after your partners death is a most private emotion. This made it a very sensitive area of enquiry. However, there was evidence that towards the end of their partner's lives, lay carers began preparations for their impending loss. The inevitability of death was accepted but it was their own future that was uncertain; 'It's a dreadful situation for me, very frightening...I think he has given up. Now it's very near... you have to accept it. The two things in life is to be born and to die' (LC1). She was considering going to live nearer her own family after his death but that was as far as she had progressed in her own plans.

LC1 Preparing for loss
LC3 Preparing to move on
LC4 Life after loss
LC5 Plans in hand
LC6 Look beyond her death

Few lay carers seemed to have talked about their futures with their partners, probably because it was such a difficult issue. Two exceptions were LC4 who had gone so far as to reassure his wife not to worry about their young son but LC5 reported that they had discussed everything and 'it was her idea that when she died, I have a holiday' (LC5).

LC3 approached the situation differently in her preparations for loss. She recognised in the second conversation how her attitude as changing, how she had achieved some of her grieving and was preparing to think of her life again, 'I don't know whether it's like compassion, when you've seen enough terrible pictures you kind of switch yourself off' (LC3) and how when you recognise that 'you can't do anything about it you've got to try and concentrate on your life more' (LC3).In her preparation she even gave away all her MND books, almost as if she realised she had to give her husband away to MND.

Work and career were obvious needs for LC4 and LC6. They both struggled hard to continue with their careers during their partners' illness. 'I'd love to do my job and look after Liz but what do I do when Liz's gone and there's no job and probably a 5 year void in my career. A future employer wouldn't really want to take a risk' (LC4). Therefore he maintained his job throughout her illness although this did stretch him. LC6 also maintained his job but looked beyond his wife's death with mixed feelings, 'I don't know whether I feel guilty about it or not but one of my personal feeling is to look beyond death' (LC6) and he had already fantasised that he would 'buy a backpack and do the South America's for a year, I won't do that but it's escaping' (LC6). In this difficult uncertain future, although they considered options, until it actually happened it seemed they could not clearly plan or predict their own futures.

7.10.1. Implications of category 'Preparing for loss'

Once the lay carers had journeyed through their shock, searched for answers, coped with life changes, learnt how to care and manage their vulnerabilities, they realised that they also had to prepare for the actual death of their partner. This meant thinking beyond the death and to their own lives. Much time and energy had been devoted to the person with MND, it was quite hard for the lay carer to consider themselves again.

Practical implications

A: Lay Carers

- economic concerns meant jobs had to be sustained throughout the periods of illness, it was recognised this would give them a focus after their partner's death
- no compassionate leave appeared to have been offered to lay carers with the promise of returning to their jobs after the death of their partner
- the need for a 'post-death event' seemed high on the agenda for the lay carers once their partner had died.
- talking with their partners about their own future appears a difficult topic

B: Cared For

- avoidance of the subject of their partner's future may have caused further isolation

C: Professional Carer

- being sensitive to the possibility of opening up a conversation in this domain may be useful

Philosophical implications

A: Lay Carers

- thinking of your life after your partners death was a stressful process
- it was so sensitive they found there was an absence of anyone to talk this through. There were notions of guilt talking it through with me. This whole area of care for the carers appeared neglected. It may be appropriate to refer some lay carers to a bereavement counsellor, even before the event, to offer support in this area.
- the need to be different again came across from the lay carers in terms of their travel ideas and escaping from the situation that had so entrapped them. They would have to create a new way of being
- being together with their spouse in the knowledge that they were to be physically parted was not an easy endeavour - only one couple really managed this

B: Cared For

- recognition that your partner's life is to continue after your own is a difficult reality. If there is open discussion between partners about the disease and its implications, this might open the way to talk about the surviving partner. This could be seen as a caring act, This could be seen as a caring act, to talk about the surviving partner and agree some future actions the survivor can take, almost caring beyond the grave. Adoption of this way of being is acknowledged as a challenging route to take

C: Professional Carers

- appreciation that the carer who has invested so much time and energy into caring for their ill partner is inevitably 'left behind' and possibly without a purpose highlights the need for follow-up care for the lay person after the death of their partner and even the option for some discussion before the death of their partner

7.11. REFLECTION HIGHLIGHTS REALITY

In parallel with the cared for, when asked how the guided conversation had influenced the lay carers, they acknowledged how talking about their experiences had highlighted their reality.

LC1 Reflection highlights powerlessness over MND
LC3 Think things through in reflection
LC4 Revelations gained from reflection
LC5 Reflection focuses reality
LC6 Reflection challenges thoughts

Half of them identified how talking was helpful, 'I think it helps me to talk things out' (LC3) because she recognised how 'you do actually shift it on to somebody else don't you, if you talk to people' (LC3).This relieved her of some of the anxieties and feelings of responsibility for a while through her sharing. She added how it was easier talking to a stranger than a relative as she felt less guilty burdening a stranger.

Another carer adds 'it was quite useful (LC6) in actually thinking about his responses to the situation in a considered light. One carer realised 'I was beginning to suspect that I don't talk to Liz about it, not address the emotional needs' (LC4). He added, 'I don't sort of recognise the stress side of things going on, it's something you just get on with' (LC4).

There was recognition of accepting the situation, 'it doesn't worry me now, it's just happened there's nothing you can do about it' (LC2) but there was also the realisation that talking about it can rekindle the pain, 'when you have to explain it to someone, [it] brings us back to the thought that, 'Well, she's only got so long to live' (LC5) and 'it emphasised the problem' (LC1). These comments reflect the different stages of working through the situation that each of these lay carers experienced across the conversations.

7.11.1. Implications of category, 'Reflection highlights reality'

Reflecting on their stories and experiences with a stranger made them consider the reality of their situations. Two lay carers did not appreciate this process although the other four recognised some value with one locating a lack of emotional provision in his caring role. The guided conversations were not developed to be a therapeutic tool but suggest that talking to a stranger can be a positive support strategy.

Practical implications

A: Lay Carers
- reflecting through speech about one's situation makes it real
- talking in the majority of cases was seen as a positive experience as it clarifies their position
- leaving the thoughts with a stranger resulted in less anxiety as to how such distressing experiences could affect them

Philosophical implications

A: Lay Carers
- different ways of being demand different approaches
- for some people, realisation of their strengths and weaknesses in caring can be verified for them and help them identify gaps in their ways of caring
- reflection offers a sense of taking stock of their situation and appreciation of their ways of caring

APPENDIX 13

EVIDENCE SUPPORTIVE TO PC GROUP CATEGORY FINDINGS

This evidence is supportive to the findings presented in chapter 8. It is sequenced in accordance with chapter 8 (i.e. section 8.4., 8.4.1. etc) to facilitate orientation.

8.4. ROLE LIMITATIONS

Role limitations were perceived as an uncomfortable admission. Two main areas are identified, the functional limitations and the external economic limitations which affect delivery of care.

Whatever effort care professionals put in, their functional skills have limited effects for a specific time period. Care for people with MND is essentially about care for people who are dying. Their role ultimately becomes a matter of 'monitoring a person's decline' (PC9). In tandem with this reality, economic constraints frustrate their attempts at providing aspects of care which can promote the quality of remaining life.

Although a unanimous aim of professionals was agreed as 'allowing them [patients] to remain as independent as possible for as long as possible' (PC9), even this approach had its end point as 'there comes a point when it[interventions are] is no longer useful to them' (PC1).

PC1 Limitations of professional role
PC2 Limitations to professional caring
PC3 Limitations to professional caring
PC4 Limitations to care
PC5 Professional constraints to caring
PC6 Limitations of professional role
PC7 Constraints on professional role
PC8 Limitations of professionals
PC9 Weaknesses in service for MND patients

Identifying this transition point is very stressful for them for professionals, 'I think it can be quite difficult emotionally that you have to be able to cope with seeing people that you are quite close to, because you work closely with them, suffering' (PC1).This challenge of an incomplete role made the situation difficult, 'I think it's very sad, unfortunate illness to experience. I think it's tragic really 'cos there's nothing we can do for it, for them to actually improve, well we can improve their life as far as we can but it's a slow progression and there's no education that can treat it and make it better' (PC6).

When functional interventions became ineffective, professionals could not justify visits. Any emotional support they had offered also disappeared. Professionals realised this was a problem as, 'there was quite a lot of informal counselling really going on there .... but my emphasis was functional assessments, equipment and adaptation' (PC9). The professionals acknowledged that this withdrawal of care left a vacuum. A conclusion reached by three professionals was the need for a new counselling role in the care of such people as 'I've picked up that for some people, professionals can only do so much with their role and something extra is needed which they cannot provide' (PC3). The consultant clearly identified that 'we don't have a specific sort of support nurse here for motor neurone disease, or such conditions. We do have a MS nurse but what I feel we really lack, is counselling......if we have specialist nurses for motor neurone disease [they] could visit and do this between clinics, it would be nice for a little support and probably the patient would feel better that there is somebody they could see immediately' (PC8).

The economic limitations were similarly frustrating for professional carers and rendered them powerless in certain situations. Five months before MND3 died his wife was exhausted with over two years of intensive 24 hour caring. The professional team requested community funding for the introduction of a social carer as night relief. This recommendation had cost implications and was not responded to. 'We put in a quote, our bids in November and it still hadn't come through by the time he died in March, it's awful really [for] someone with a short life span like that' (PC3).

The caring team appreciated that economic pressures meant assistance might come too late so they had also explored other options 'through contacting the MNDA they have been willing to fund short term money for this and this is again in exceptional circumstances and for very short term ..until health monies are available' (PC2). It appeared that within the health and social division, whenever the need was not clearly a social or a health need, each department would expect the other department to be financially responsible. The caring professionals realised that such a situation leads to increasing delays for people with MND. This is why they extended their search for help into the voluntary sector, where they found financial support.

The financial managers were far removed from the point of suffering. This was the perceived rationale for the economic limitations placed on professionals and ultimately the patients. In exasperation the nurse specialist, (disability) remarked, 'I mean this is a really sweeping statement ... but they're not at the ground level, they don't see the implications of caring, what people go through to maintain their loved one at home for as long as possible. I mean, his wife could take what I see as the easy option and say, 'No, I'm not having him at home anymore, I've had enough'. He could go to a nursing home and that would be more expensive, looking at it from a purely financial view and if they put a little more effort into realising what carers do and what patients have to live through well, I think they'd perhaps come up with the goods quicker' (PC2).

Equipment shortages in the NHS created a similar frustration for the speech and language therapist, 'I've tried to stress in my letter to the Health Authority (asking for the purchase of light-writers), to explain what its like not to be able to communicate and how that affects your dependence and independence... you become dependent on others if you cannot ask for things but more than that you cannot express your personality.. you can't share jokes, you can't talk about the weather or what's happening in politics' (PC1). She continued in her quest for money to buy light-writers but was unsuccessful. She had to live with the frustration that she could not help people in this way with communication difficulties. She asked the MNDA, on occasions, to fulfil her professional judgement of a care need as they could supply such equipment on occasions.

8.4.1. Implications of professional category 'Role limitations'

Role limitations were identified as aspects of care that could not be delivered due to lack of personnel, time, money and equipment. This led to frustrations for the care professionals as they could not attain their ideals of care.

Practical implications

A: Professional Carers

- all the professional carers with continual patient contact, (PC1,2,3,5, 7,9) felt passionate and disturbed about the lack of economic resources available which acted as a constraint to the care they desired. Letters of compliant to the financial managers had no impact.
- the gap in emotional care for people with MND was considered a reality and needed attention
- the development of a specialist nurse for people with MND who could offer specific counselling and support was a valued potential development

B: Cared For

- economic limitations on care can mean false promises and raised expectations that cannot be attained through health and social services
- limitations of equipment can lead to unnecessary hardship whilst dying
- lack of professional time is detrimental to care

C: Lay Carers

- lack of practical support through economic restraints makes their lives harder and may force them to stop caring at home. This would have higher financial implications to health and social services
- lack of professional time is detrimental to care

Philosophical implications

A: Professional Carers

- role limitations need to be brought into the consciousness of professional carers and the nature of these limitations appreciated
- care for the 'being' of another is equally important as care for the body of another person but seems a neglected area in MND due to the professional functional emphasis
- a new role should be considered for patients who are under severe emotional and physical duress. The need for a Macmillan type MND nurse could be an option
- professionals would need emotional support if they were to offer more to patients

B: Cared For

- emotional limitations on care receipt can lead to further isolation, false expectations and increased suffering for the cared for
- professional emotional care is needed by patients

C: Lay Carers

- lack of emotional support for themselves and their partners can lead to further suffering, isolation and relationship difficulties
- professional emotional care is needed by lay carers

8.5. SITUATED FRIENDSHIP

Emotional support when offered was through the vehicle of a situated friendship. This involves professionals adjusting their demeanour and values to meet those of the patient; trying to fit in with their life-styles; emotional labour; keeping the focus of care on the patient.

The idea of a situated friendship arises from professional carer motivations of 'wanting to provide the best that there is... as a friend' (PC3). Friendship invites a level of commitment, a motivation to locate the other person's frame of mind and to respond to their needs. It is 'situated' as the friendship originates from the diagnosis and only lasts whilst the care is being delivered. It was not an ideal of care but an action of professional caring attained by five professionals towards MND3/LC3.

PC3	Responsive friendship
PC5	Responsive friendship to meet patients needs
PC6	Adjusting to patient's stance
PC7	Responding to patients' demeanour
PC9	Responsive close relationship

The PC-MND relationship has been described as 'sort of professional but friend as well...it's not like a close friendship that's going on forever, it's sort of a limited time friendship that they can call on in time of need but once everything's sorted out then it will fade unlike a proper friendship that goes on for years' (PC3).

Time was a critical factor in the level of friendship attained. The five professionals that spent most time with MND3/LC3 agreed that it results in a closer relationship, 'you have a close relationship with them and you have a long way to go with them' (PC9). The primary focus of the situated friendship rests on the needs of the patient. The professionals did not expect a reciprocal arrangement as 'part of being a professional is being able to disengage your own personal feelings... I have to find the best way that they want me to interact with them really' (PC5). This did not mean that the professional did not offer information about themselves when appropriate but was actualised with an exaggerated respect for the patient's autonomy in that. 'I think you have to recognise the fact that you do have your own values and you have to recognise the fact that you have to try to shelve those values while you're doing that work for a particular person.. in acknowledging that you can begin to think about ways of not oppressing people' (PC5).

Not all professionals wanted to gain a relationship of any sort with MND3 . The dietician spoke that *'I haven't really tried to develop it... I haven't consciously tried to develop it'* (PC4). She saw them once every month at the hospital rather than in their own home and considered her functional intervention the main feature of her involvement.

For others, an element of 'emotional labour' is identified as being a component of a 'situated friendship'. This requires a reflexive demeanour, trying to adjust to the patient's mood and temperament at their appointments. The district nurse recognised the importance of trying to emotionally 'fit' with patients rather than in contrast to them as. 'I mean I might be feeling lousy like I have this morning and I've been putting on a beam everywhere' (PC3). The physiotherapist suggests that in the course of a day, moving from one patient to another becomes quite a challenge as you may be 'having to be very serious and very sad and perhaps going to someone who's completely opposite and it's hard then to quickly change from being one type of person to another type of person' (PC7). The 'emotional labour' is effective in promoting and sustaining a situated friendship but the professionals accepted this value was not true for all professionals, 'you try and gauge what their attitudes are when you first see them because you have to alter the way you tackle different people .. but I don't think all professionals adapt to the patient. You hear about situations that the patients have come across when somebody hasn't adapted and that's when clashes happen' (PC7). Attempts were also made to fit in with patient's lifestyles. Sensitivity when trying to arrange appointments was seen as important, 'I'm trying to fit in with their family lifestyle... we're just visitors' (PC3).

Although there were no reported clashes between the professional carer participants and their MND patients, the most junior professional stated she only had one approach, , 'I just try to be happy all the time from them.... I just feel that's probably the best way'(PC4), rather than think about trying to appreciate the other person's frame of mind and adapt accordingly. Such joviality might not always be the most sensitive of approaches under all circumstances but could be seen as a personal protective mechanism.

Working closely with people with a terminal illness and offering a situated friendship can take its toll on the professional carers. It made the nurse specialist admit 'I know one shouldn't get emotionally involved but you just can't, I can't help it' (PC2). Even at the official starting point of the disease in the telling of the diagnosis, it can stress the professional ,'it is quite awful really to tell the diagnosis, it does upset me, it's unpleasant' (PC8). In more general terms the physiotherapist reflects how, 'you just drive past all these houses and you don't know what goes on inside them' (PC7).

Caring for someone with MND, getting to know them through a situated friendship and watching the progressive effects of the disease can be 'emotionally exacting' (PC6). The professionals realise that they may also need support in these situations. The most common approach reported was turning to colleagues as, 'talking with the other physios.. we discuss what's she's doing and whether she needs my help… we have each other.. but if I didn't have them I suppose it could be different' (PC9). However, a caring situation could be made more challenging if there were personal parallels between them and their patients. This could affect them in one of two ways; make it harder for the professionals as they would identify with the age of the patient and realise how close such suffering was to everyone particularly if, 'it could mirror some of your personal situations then it's more difficult' (PC1). Equally, personal parallels between professional and the cared for could result in more support for patients as suggested by the occupational therapist, 'I think with them [MND/LC3] we got it just right, but I think there were factors because of our understanding and age' (PC9). This situation brings them more into line with the experiences of being a lay carer.

8.5.1. Implications of professional category 'Situated friendship'

Situated friendship relationships were desired by clients and supported by the majority of professionals. These professionals adjusted their demeanour and values to meet those of the patient. They tried to fit in with patient life-styles during their visits and they 'emotionally laboured' for the patient's benefit. In a situated friendship, the focus of care remains squarely with the patient. The patient's needs come first and the professional adapts to the situation of need to delivery the best care they can in this frame.

Practical implications

A: Professional Carers

- a 'situated friendship' offers a relational vehicle for maintaining the focus of care with the cared for
- a situated friendship means the professional adapts to the patients' demeanour and lifestyle but not all professionals are willing to do this which can then lead to problems
- care for professionals is sought from their colleagues but this care might not always be available
- organised support for professionals was absent i.e. clinical supervision

B: Cared For

- maintaining the focus of care on the cared for offers a sense of valuing and remaining human which is their central value
- when their central value is not realised this can lead to distress and suffering

C: Lay Carers

- if a professional can offer a situated friendship then this could be extended to the lay carer as well

Philosophical implications

A: Professional Carers

- emotional labour is required to maintain a situated friendship
- a situated friendship may involve suspension of one's own values in order to support the needs and decisions of the cared for
- a situated friendship supports the cared for as a human being first and is linked to their ideals of care

B: Cared For

- a situated friendship from professional carers keeps the primacy of the patient
- is also promotes respect for the patient's autonomy
- and it maintains the cared for as valued, as being human

C: Lay Carers

- a situated friendship with professional carers keeps the primacy of the patient

8.6. LEARNING THROUGH EXPERIENCES TO CARE

The professionals all realised that learning to care is a continuous process and should be implicit in being professional, 'I think if we realise and are open to that, that's helpful' (PC2). They all agreed how experiential learning instructed them not to make assumptions of patient's level of understanding about MND; to learn from patients by focusing on the patient's ways of being and needs rather than solely their professional perspective; to use themselves in listening, being attentive, empathetic, drawing on personal experiences of care and having an openness to learn about the needs of others; and finally teaching others these ways of knowing in caring for people. This learning clarified their professional knowledge as well as potential for new knowledge.

PC1 Educational imperatives: helping others learn to be cared for
PC2 Openness to learn
PC3 Learning through caring
PC4 Novice learning about care
PC5 Learning through experience
PC6 Learning about MND care
PC7 Learning sensitivity through experience
PC8 Learning through experiences

When challenged with MND, the majority of professional carers had a steep learning curve. The GP confessed, 'I had to admit to him (MND3) my lack of knowledge and how I'm sort of learning as he was ... that I would find out as much as I could and we'd do our best as a team to make everything work as well as we could' (PC6). The district nurse admitted to not knowing much about MND but adopted the attitude, 'I think if you've got something you don't know very much about you have to try and learn as much as you can' (PC3). The experienced physiotherapist remarked, 'my first couple of patients with MND were a steep learning curve and you go and see them and you haven't got a clue what's going on, you have to read up a lot initially to find out what's happening but after a while when you've seen several patients you get an idea of what sort of problems are going to occur' (PC7).

The consultant had a great deal of experience with MND but he recounted examples of his experiential learning for telling a person their diagnosis as 'nobody teaches you'(PC8).. 'over the years you tend to have sort of an understanding of what people's concerns are' and how to approach them with such awful news. He learnt to evaluate his performance as well using the criteria that if a 'patient's happy [it] is [your] measure of success' (PC8).

An important lesson learnt by the speech therapist was, 'whenever I meet someone for the first time I will say to them, 'Oh, what do you know already?', it's so easy to assume they've been sat down and counselled and come to terms with it' (PC1). The speech and language therapist learnt how patients are often given little information beyond the diagnosis. In a similar vein the nurse specialist learnt 'You have to be careful .. there are other people who don't want to know about the future and who can only cope with today ... you have to be very careful when you're explaining these things' (PC1).

Focusing on the person with MND is an important aspect learnt by the speech and language therapist and dictates how she approaches patients. She recognises their frustration potential when their communication ability reduces and how they need someone to be patient and listen to their sorrow,

'I'd tend to be there to soak it up 'cos sometimes they need to off load it and you've actually got to ....to take it on your shoulders 'cos they need to share it with you and if you're going to stand with somebody and listen to that then you need to be able to take that on board' (PC1).

Another professional carer realises that listening is the best approach to clients as hearing what they wanted 'was the most important thing, I felt' (PC9), as it confirmed the needs and distress the patient was experiencing. Using self through listening was considered a vital professional ingredient, 'willing to listen, a good listener but perhaps not just listening but takes action on what they've heard in a way they wanted it to be done (patient), not in the way that they feel it should be done (professional)' (PC2).

Learning the importance of empathy is best illustrated by the following comment, 'I try to put myself in the carer's position, as well as perhaps the patient's position; what would I feel like being her or how would I feel like being him... I think they want empathy as much as people are able to be empathetic.... I've tried very hard to understand what it's like and that I let them know that's what I'm doing' (PC2). Talking about learning to use self in caring was sometimes challenging to articulate, 'gosh, this is quite hard. I think you need to be caring... you have to be sensitive for certain needs' (PC4).

Willingness to learn was identified as an important feature of using self. It was perhaps easier when faced with less common conditions as expectations to know may be reduced, 'MND is such a rare condition to have to work with that it, it made me more sensitive to being open-minded (PC2). The district nurse shared how personal experience was a useful source of learning about self in caring for people, 'I've been a carer too and I know how important it is if somebody comes in and says, 'Well, how are you feeling?'' (PC3). Overall, the value of learning from experience is undisputed, 'I think because I have had experience with other patients then I understand what their needs are' (PC7) although of course not everyone had these experiences.

Being receptive to clients' need to establish a dynamic normality was only identified by two professionals. The speech and language therapist recognised how they 'want to keep to the normal' (PC1) but how difficult this is in the domain of speech problems. Speech therapy tries to maintain speech for as long as possible as 'most prefer to want to talk' . Using a light writer is 'incredibly slow compared to speech.. he would try and speak because even in great difficulty it was quicker' unfortunately ' … there comes an a point when it is the better alternative but it's very slow' (PC1). A false normality was recognised as an important element by the nurse specialist as in her co-ordinating role she stated, 'I mean I know life wasn't in any way normal for him but he still had his job to go to, he still had his family around him and that's what he wanted to maintain as much as possible' (PC2).

Teaching others

Linked to one's own learning through caring comes teaching others. This is regarded as an important part of professional carers role in terms of teaching people with MND, their lay carers and student colleagues. Although the consultant admitted to not receiving educational support in telling a terminal diagnosis he tries 'to teach the students when they come to out-patient about how to handle [this]'(PC8). The physiotherapist adopts the strategy of discussing individual cases with students, 'I'd be asking them what they thought about this and what other insight did they have … what their thoughts were and did they see everything that I saw?'. This debriefing by an expert allows students to see for themselves and through their experienced colleagues to 'work through what went wrong and to talk about what would have been better had they'd approached it in a different way would they have had a better response. It's getting people to reflect on what they've done' (PC7).

For patients, the speech and language therapist realised how patients 'want to understand why the problem is there. She acknowledges that through teaching patients the reasons behind their problems they have said to her, 'you were able to sit and explain time and I understand perfectly now and that makes me feel a lot better' (PC1). This educational function is congruent with patient need as explained in the MND category 'Importance of creating meaning'.

The range of skills that might be taught to a lay carer are phenomenal when considering it from the physiotherapist's perspective, 'his wife has had the steepest learning curve I know... she's gone in two years from not knowing a thing to do with medicine to being a very competent carer, being able to handle suction machines, gastrostomy tubes, bowels...' (PC7). All these skills had to be taught by the health professions.

8.6.1. Implications of professional category 'Learning through experience to care'

Learning through experience means learning from events with others. This often meant learning from patients and lay carers. The fact that the professionals had an openness to learn and a willingness to accept they do not know all the answers is a significant finding. The various elements of their learning highlight their motivation to offer the best care they could through responding to the needs of their patients with sensitivity.

They all agreed how experiential learning instructed them not to make assumptions of patient's level of understanding about MND; to learn from patients by focusing on the patient's ways of being and needs rather than solely their professional perspective; to use themselves in listening, being attentive, empathetic, drawing on personal experiences of care and having an openness to learn about the needs of others; and finally teaching others these ways of knowing in caring for people. This learning clarified their professional knowledge as well as potential for new knowledge.

Practical implications

A: Professional Carers

- learning through practice is a central resource to develop caring practices
- sharing knowledge about symptoms alleviates patient's anxiety
- not knowing is not a preclusion to finding knowledge
- not knowing does not amount to not caring if information is sought
- teaching others what one has learnt experientially about how to be with patients focuses ways of being to students
- reflection on practice is a useful mechanism for learning
- learning about a patient's need for a normality means it can be facilitated by professionals
- learning how to use self is not a well articulated process that needs development with professionals

B: Cared For

- awareness that professionals are learning as well as the cared for may be unnerving on occasions and reassurance may be necessary
- professionals teaching patients has enormous benefits for supporting patients

C: Lay Carers

- teaching lay carers has enormous benefits for patients who wish to remain at home and may boost lay carer confidence
- there is a danger to teaching lay carers, it may further pressure them to undertake some practical caring functions that they find disturbing

Philosophical implications

A: Professional Carers

- professionals should recognise their continual becoming in their professional roles through learning and remain open to potential learning opportunities
- conditions in a person need to be right to learn including openness and motivation,
- those professionals who have underlying values of wanting to offer the best care possible appear highly motivated to learn more
- learning from patients can offer opportunities for new ways of being that transcend professional education

B: Cared For

- if professionals put the patients first and listen to them to learn, this is a valuing feature that may have therapeutic implications for patients

C: Lay Carers

- listening to lay carers concerns and learning about problems encountered promotes effective care at home

8.7. CRITICAL NATURE OF TIME

The critical nature of time captures two dimensions; first, professional's recognition of the short time MND patients have left highlights the urgent need for equipment and services and second, how professionals themselves have little time in their busy working lives to offer the care they want to deliver. Although the second point is also a limitation of professionals, its specificity rendered it part of this distinct category.

PC3 Temporal urgency of action
PC6 Shortness of time for patients
PC7 Time focus
PC 8 Support for short living time
PC9 Critical nature of time

The professionals realised they were in a race against time when dealing with MND, 'they don't want to wait another week or a fortnight, they really want it organised because they haven't got that much time… then they can get on with what life they've got left' (PC3). The occupational therapist was particularly pressured in gaining equipment and she remarked, 'ever since I've been in social services we've been saying there should be a pool of specialist equipment' (PC9) but so far this goal had not been realised or funded. She would sometimes hold on to some equipment to have it ready.

Aware of the shortness of time for people with MND made the nurse specialist, 'want things to be done there and then and I know they can't …..as somebody with MND you want it done there and then' (PC2). The stress on care professionals in organising services was high, particularly when they met with delays or resistance. There was the genuine commitment to help people which led to the feeling of 'let's get this sorted' as 'I think MND is a very difficult illness… in terms of management I think it just accelerates how you do things' (PC5).

An interesting feature in realising the critical nature of time was how MND compared in service provision to cancer patients, 'I mean people usually pull out all the stops for the terminally ill and the Hospice for cancer patients is very useful; but I think the Hospice will provide equipment for a cancer patient but they don't seem interested in motor neurone disease…… the MND patient's needs are just the same as the person dying from cancer really' (PC7). This comparison but difference in care provision highlights a perceived gap in care for people with MND.

Unfortunately, the professionals were very busy practitioners and were unable to offer much time to the cared for, 'you only have a certain amount of time so I'm always thinking, 'I can't, mustn't really spend longer than half an hour with this patient'' (PC4). The pressure not to spend time was identified as top driven as, 'when the managers try to examine what we're actually doing, you're not making the patient better, how do you measure support, you know, handling advice?' (PC7). This pressure hastened their withdrawal when their functional interventions were no longer helpful. They could not justify their time at that point, even though they recognised the need for emotional support.

Lack of time was blamed for low visiting rates. This was balanced by the GP as a possible positive outcome, 'some GP's might say perhaps they should be visiting more often but to have so many visitors, I don't think that's appropriate really 'cos their time is limited as well' (PC6). The feature of time was as critical for people with MND and for the professionals.

8.7.1. Implications of professional carer category, 'Critical nature of time'

Criticality of time was reinforced by professionals through the imminent death of their patients. Equipment shortages create frustrations and personnel shortages limit time for patient visiting. Ideals are unhelpful if there is no time to put them into practice. The lack of time for patients was identified by the lay carers who felt that professional visits were infrequent and brief.

Practical implications

A: Professional Carers

- time was a critical feature for the cared for and this gave the professionals a sense of urgency
- time that could be spent with each patient was short, professionals had high workloads which increased their pressure
- care professionals were frustrated with the amount of time it took for equipment to be organised, lack of a central pool for equipment meant there were delays for patients
- as non-functional aspects of care are not measured this magnifies pressure for professionals to justify this aspect of their patient interaction

B: Cared For

- busy professionals were unable to offer the time needed, particularly to help with the emotional aspects of their situation
- without a central pool of equipment, there were many delays in essential items which could have made their last days more comfortable

C: Lay Carers

- busy professionals were unable to offer the lay carers the time they may need, particularly to help with the emotional aspects of their situation or to always find out what the problems were
- extra equipment to meet need would have supported the lay carer as well as the cared for

Philosophical implications

A: Professional Carers
- the importance of being in time was realised by the professionals for the cared for which made them anxious about the impact of organisational constraints

B: Cared For
- not receiving vital equipment and limited interaction with busy professionals impacted on feeling valued. It heightened feelings of vulnerability as they would not be in a strong position to complain due to MND

C: Lay Carers
- waiting for the death of a partner and for equipment and experiencing short interactions with professionals is not conducive to positive care delivery

8.8. IMPORTANCE OF INTER-PROFESSIONAL CO-OPERATION

Many professionals can be involved with MND patients but it is unusual for organised inter-professional co-operation, 'It's very much down to whether the local team are interested or not' (PC7). This reference to a local team did not assume one existed for people with neurological problems, it referred to professionals in a catchment area. They would receive referrals for aspects of a persons care on an individual basis.

The importance of inter-professional co-operation is highlighted by the district nurse, 'well, the dietician's involved with the diet, I was involved with the diet and the speech therapist was involved with the diet and the GP had to prescribe it.. the carer had to know how the feeds were to be given so that's five of us who would be involved in just feeding him' (PC3).

The MND3 professional carers were organised by a co-ordinator as problems had arisen, 'he was having problems with the co-ordination of the services. There were a lot of professionals involved but there was not a named person who was co-ordinating things' (PC2). This co-ordination role allowed patient, carer or other care professional to communicate through this one person. They could seek an update on his progress and the interventions of others. Professional co-ordination was agreed to be a positive development by the cared for, lay carers and professional carers in this team. Evidence from the MND/LC participants who did not enjoy co-ordination illustrates its benefits (see MND strengths and limitations of received care and LC strengths and limitations of professionals).

PC2 Importance of inter-professional communication and co-operation
PC3 Inter-professional co-operation
PC4 Inter-professional liaison
PC5 Importance of professional liaison
PC6 Value of professional liaison
PC8 Liaison with other professionals
PC9 Inter-professional co-operation tensions

The professional who did the co-ordination was a subject for debate. Criteria for choice appeared to be in favour of the professional having the most pivotal role. The consultant saw the GP as, 'the most crucial person really' (PC8). The occupational therapist suggested, 'either the OT or the social worker be the care manager but there are big issues here really' (PC9) as if you are care manger on a big case it restricts the amount of care you can deliver. Although there were differences in who should be the co-ordinator, the fact that there was a co-ordinator was valued and reported as being effective in promoting inter-professional co-operation.

The co-ordinator was available for 'advice and help getting thing done, she's great. If it's a problem I can't sort out easily here, I leave it with her, she usually does' (PC3). She facilitated the case conferences which included the clients as well as the professional team. They were held at the GP's surgery and although they are 'not the norm, it's working well' (PC7).The co-ordinator worker and case conferences allowed everyone to know, 'exactly who you are, where you're based, your phone number' (PC3) as well as planning and clarification of roles and input.

The occupational therapist stated she 'thought the case conferences were good.... With MND3 and LC3 there they were able to ask any questions and I mean we were working well together, I think you have to really, there were an awful lot of people involved' (PC9). In addition, if anyone could not attend the meetings there were joint 'notes that were actually kept at their house so we could refer to them and write in what we were doing' (PC9).

The GP remarked how they were 'a reasonable way of gathering information. Some GP's may not like that but it didn't really take up much time really, only half a hour, once every two months (PC6). The consultant also supported the idea although 'Its difficult with the timetable to attend but if there is the possibility of attending, yes, I do' (PC8). The physiotherapist wanted similar conferences with other MND clients on her case load but 'It depends on who the team members are, if they're keen to do it. I'm trying to start off with another patient at the moment but the district nurse doesn't seem keen' (PC7)

People not invited to these case conferences were representatives from the motor neurone disease association. However, repeatedly care professionals would liaise with them for equipment or advice as the MNDA would always be 'very speedy'(PC7) and help the professionals as well as the people with MND. One professional stated, 'on the phone they were interested and they wanted to send out pamphlets very quickly to us' (PC3).The MNDA also had more specialist equipment which were life enhances rather than physically essential, 'with Henry we had a very specialist type of page turner which I got through the MNDA and would have been difficult for us to fund really' (PC9).Despite this omission, the team approach to care meant all the professionals knew each other and this aided inter-professional co-operation to the benefit of the patient and lay carer. It also promoted continuity of care which was desired by the cared for and lay carers.

8.8.1. Implications of professional category 'Importance of inter-professional co-operation'

Many professionals become involved with people who have MND. Inter-professional co-operation can be enhanced through a professional team co-ordinator. Case conferences permit them all to meet and discuss progress and problems, and include the cared for and lay carer.

Practical implications

A: Professional Carers

- without co-ordination there are no clear boundaries or potential for co-operation. This can lead to duplication omission of function and places further pressures on the clients
- the co-ordinator would be effective in reducing overlap of boundaries between the professionals which is cost effective and effort effective and less confusing for the patient
- communication problems are reduced through a co-ordinated team approach involving the clients as well as professionals
- the co-ordinator spends time chasing up equipment and resources leaving the other professionals to deliver the care

B: Cared For

- a co-ordinator meant only one person need be contacted
- problems would be managed by the co-ordinator who could alert the appropriate care professional rather than the client
- a co-ordinated team approach meant the clients could get to know their professional carers and develop desired relationships
- problems could be solved more quickly by a co-ordinated team

C: Lay Carers

- lay carers wanted continuity of carers and co-ordination of professionals to reduce their feeling of being overwhelmed by so many professionals
- co-ordination helps in the organisation of timed visits and interventions
- co-ordination assists lay carers in their relationships with professionals and allows them to have assistance in selecting the most appropriate advisor for each problem

Philosophical implications

A: Professional Carers

- there was some debate concerning who should be the co-ordinator. Subsequent co-operation illustrates how professionals can accept each others role as complementary rather than n context. A co-operative way of being is possible
- there remains professional resistance to inter-professional co-operation. This change in ways of working practices needs to be focused to promote quality care and efficient use of resources
- complex patient care demands multidisciplinary interventions and co-operation
- team conferences served to unite the professionals and the specific client team

B: Cared For

- the approach increased a sense of client participation and being valued

C: Lay Carers

- the approach increased a sense of client participation and being valued

8.9. CONTINUUM OF REFLECTIVE THINKING

When asked how the two guided conversation had influenced them, the professional carers gave a range of responses. Three reactions were noted; the first was that they were too busy to think about the conversations. As I had left them they went to the next patient; the second was evidence of reflection as the conversation 'made me think what I had done for those people I'm involved with' (PC2). The third reaction was not to think about it until they received the transcript and then seeing the conversation on paper made them more analytical. (two participants offered no comments).

PC1 Reflection made thinking time
PC2 Reflective thinking
PC5 Reflection as thought provoker
PC6 Too busy to reflect
PC7 Reflective benefits
PC8 No explicit reflection
PC9 Usefulness of reflection

The most experienced practitioner with MND had the least reflective outcome. He stated, 'I don't think there was any thing specific' (PC8) that came to mind after the conversations.

Two practitioners admitted being very busy at the time of the conversation so 'Everything does get forgotten fairly quickly in that we tend to go from one thing to another ' (PC1) and 'I was going through a busy time actually, it was just put aside and I moved on' (PC5). However, 'It wasn't until I received the transcript I think it really hit me' (PC5). The benefits of being reflective at this time were the social worker recognising 'we need to think about a strategy in dealing with that because MND needs to be fast track' (PC5). The speech and language therapist recognised 'I haven't thought much about how we support each other within the department.... It was something I'd never really thought about' (PC1). She realised this was an important gap in the department.

Four professionals did state the conversations had made them think about clients. The GP stated, 'You've made me think I ought to phone her again and see if she'd like me to visit' (PC6), this was after MND3 had died and the GP was considering her lack of follow-up care. The physiotherapist had found the conversations very interesting and suggested how 'putting things into words makes you think abut what you're talking about, so you think about your feelings about people with MND' (PC7). It could be inferred that an absence of talking about feelings does not permit analysis and may limit professional and personal growth.

The occupational therapist admitted she did consider it 'because I don't think that we sit down and analyse how we approach things and we should do that more, so the questions you asked were very thought provoking' (PC9).

8.9.1. Implications of professional category 'Continuum of reflective thinking'

The busy nature of professional life certainly seems to be a barrier to reflective thinking. The evidence suggests reflection is useful and written refection can be supportive in busy lives. Positive strategies for practice delivery can be identified.

Practical implications

A: Professional Carers

- the busy nature of professional life certainly seems to be a barrier to thinking about events of the day or feelings and attitudes
- for the majority, talking about the care they offer and its effects on them and their patients has a positive learning outcome
- non-reflective practitioners can lead to stale practice
- written reflective accounts can help stimulate reflective thinking

Philosophical implications

A: Professional Carers

- being too busy prevents being thoughtfulness and so may lead to automatic practice with little scope for learning.
- reflection needs to be a valued activity to being a professional
- adopting reflection in their work practices is considered important to support professional in their stressful work practices

APPENDIX 14

EVIDENCE FOR 'GAP AND MATCH' IDENTIFICATION BETWEEN THE THREE PARTICIPANT GROUPS

This evidence is supportive to the gap and match identification presented in chapter 9. The sequencing begins at 3 for the purpose of this appendix as the first two categories are presented in chapter 9 (9.3.1. and 9.3.2.)

3. 'IMPORTANCE OF CREATING MEANING'

This MND category has a parallel LC category of ' Searching for answers' but no comparable PC category although two PC categories are drawn on 'Situated friendship' and 'Learning through experience to care'. This patient need is concerned with making sense of their new situation and trying to find some answers.

MND Practical implications

A: Cared For

- there is a need for available literature and information on MND to be readily available for people diagnosed with MND, to include its possible causes, trajectories, treatments, sources of help and interventions
- there is a need for people to have opportunities to talk through this type of information with professionals and lay members of agencies such as the MNDA

Divergence/Convergence analysis:

Most professionals had little experience, understanding or knowledge of MND. They were able to find out information to pass onto the patients/lay carers but as many PC's had little experience they often drew on the MNDA resources to learn themselves. This meant the cared for often had a time delay in receiving information so the literature was not readily available. Offering the newly diagnosed people information about the MNDA did not appear a routine process at diagnosis. It was rather a haphazard practice of how patients appreciated the existence of MNDA. The only professional immediately available to talk through MND was the diagnosing consultant, usually in out-patents, but if the diagnosis was offered in a hospital situation then ward nurses would be available. Both OPD's and wards had MNDA leaflets.

The participating consultant identified the need for a neurological nurse specialist be available for patients to discuss their anxieties further following diagnosis. Overall, there was a lack of professional people to support families at the beginning.

B: Lay Carers
- seeking meaning is a human trait and requires support rather than opposition
- technical information can be sought through professional and volunteer agencies
- human meaning is a complex construction and takes time to construct

Divergence/Convergence analysis:

Meaning appeared to be sought between cared for and lay carer with factual information gained from professionals and the MNDA and experiential information gained from MNDA. Much time and effort was invested by the lay carers in securing information for them and their partners as there was no information sheet readily available.

C: Professional Carers
- questioning from patients is part of their quest to create meaning and should be responded to with sensitively and honesty
- meaning making can be helped through clear, careful and accurate technical information.
- there is a strong role for care professionals to explain aspects of their work to patients and lay carers to ensure that understanding is achieved to facilitate areas of meaning to be made

Divergence/Convergence analysis:

The lack of technical information was a gap and also the lack of experience within the professionals. However, professionals made every attempt to learn about MND themselves as quickly as possible and to secure reading material for patients and lay carer as soon as possible. There is a clear need for information to be at hand, contact numbers to be readily available as written material is vital for people to reflect and re-read information to help them make sense of their new predicament, which should incorporate information for lay carer support networks and assistance.

Gaps in practical provision	*Match in practical provision*
Adequate instant written information about MND The offer of contact routes to MNDA Lack of experience in care professionals with MND to talk immediate issues over with them	Professionals did make efforts to attain written materials and learn about MND

MND Philosophical implications

A: Cared For

- we need to make meaning for ourselves although it is influenced by our histories, prejudices and information gained
- seeking meaning is a common human trait
- love and relationship are vital components of meaning in human lives

Divergence/Convergence analysis:

As meaning about the why's and wherefore's of MND were being sought a higher meaning came to light, that of their relationships, particularly with friends and families which offered them a more positive meaning context.

B: Lay Carers

- seeking meaning is a common human trait
- one's values influence personal meaning construction but discussion with others may assist its development (MNDA volunteer, chaplain, doctor, friends, loved ones)

Divergence/Convergence analysis:

Lack of professional assistance related with reaching out to others to help with making sense of their situation. The amount people available helped to dilute the responsibility and strengthen the lay carer

C: Professional Carers

- meaning needs to come from the patients themselves, as professionals one cannot make it for them although communication can be supportive in this area

Divergence/Convergence analysis

Appreciation of the need for people to make meaning out of their situation was not forthcoming even though professionals did respond to the need for literature on MND.

Gaps in philosophical provision	*Match in philosophical provision*
No-one immediately available to talk through the situation and be with the patient and lay carer as follow-up No evidence to identify professionals realised people need to make meaning out of their situation	No clear match

4. ‘ IDEALS OF CARE’

This professional category has no direct comparable categories from the cared for or lay carers. Essentially the ideals of caring involved three ethical stances -principled ethics, holism and caring ethics. The main categories that link with the implications from ‘Ideal of care’ are identified as the MND category ‘Strengths and limitations of received care’ and the LC categories of ‘Strengths and limitations of professionals’, ‘Vulnerability of being a carer’ and ‘Preparing for loss’.

A: Professional carers

- ideals are the basis for practical interventions and can be positive when they match with the patient’s ideal of care
- ideals do not always match reality due to limitations of role
- all professionals have ideals which are ethically based even though there may be contextual interpretations

Divergence/Convergence analysis

‘Ideals’ indicates that the care professionals have ethical stances which supported and guided their practices. This realisation means that professionals approach care as an ethical endeavour in both its practical and emotional delivery. Lay carers and the cared for value being seen and treated as human being first which demands an ethical/moral stance in any interaction as it promotes sensitivity, respect for persons, listening and appreciation of the meaning of being. However, although professionals professed these ideals, the external influences of education and context meant that their ideals did not always result in ideal practice. The MND and LC categories drawn upon as mentioned above highlight gaps in listening, sensitivity, appreciation of the meaning of being and engagement with clients although it is acknowledged attempts are made as individuals in the PC category 'Situated friendship'.

B: Cared For

- if a professional has ideals of care which are rooted in principled ethical structures then these lead the professional to respect the patient's autonomy which leads to respecting the patient as a person which is congruent with the patient's needs.
- if a professional does not have ideals of care rooted in ethics, this could present problems
- an element of protection is offered the patient, from neglect or abuse if professionals have ethical ideals

Divergence/Convergence analysis

In terms of general behaviour, atmosphere and demeanour, professionals drew on their ideals for positive personal interactions. However, their ideals were mainly focused on principled ethics rather than caring ethics which meant professionals did not appreciate or investigate the deeper ontological issues and appreciate the cared for and lay carers 'reality' experiences and needs.

C: Lay Carer

- an element of protection is offered the lay carer, from neglect or abuse if professionals have ethical ideals

Divergence/Convergence analysis

Ethical ideals permitted some insight into the plight of the cared for and lay carers but as most were guided by principled ethics their practices did not meet the deeper ontological needs of the lay carers

Gaps in practical provision	*Match in practical provision*
Ethical stance was mainly based on principled ethics which led to neglect in ontological or relational aspects of care	Ethical ideals were drawn upon Respect for humans was a clear motivator for practice

Philosophical implications of 'Ideal of Care'

A: Professional Carers

- ideals and action can present a dissonance in practice (theory-in-use and espoused theory) and be a source of frustration for carers
- awareness needs to be raised between what one's ideals are and how one practises
- being considered a human being is important ideal for some professionals as well as patients
- contextual interpretations of ideals of care could lead to tensions in delivery of patient care if these interpretations are not shared inter-professionally
- Three approaches to ideals are identified, principled ethics, holism and caring ethics. The first two categories had more membership than the caring ethics approach which suggests that mutuality and reciprocity aspects of care are not high on the professional agenda

Divergence/Convergence analysis

An ethical stance was required by the cared for and lay carers to inform practice delivery. Being human however was mainly based on principled ethics of promoting autonomy, respect for persons, honesty which led to neglect in more ontological or relational aspects of care. Although all professionals talked about their ideals of care, only four professionals talked about caring ethics of being personally involved as human to human, recognising suffering, being grounded in the patients world, seeking understanding and social interaction with a patient to reduce suffering. Holistic ideals were voiced but due to lack of continuity of carers and time constraints its holism may have been willed but was not often realised. The family context may have been noted and some aspects of the cared for's context but actual practice based on such knowledge was sparse.

B: Cared For

- ideals of care that are congruent can only facilitate care receipt but difficulties would emerge if there was dissonance
- a professional's lack of ethical ideals of care would diminish the patient's sense of being human

Divergence/Convergence analysis

Convergence was attained in principled ethics but the divergence lay in the more relational caring ethics and holistic approaches. These were gaps rather than dissonance.

C: Lay Carers
- ideals of care that are congruent can only facilitate care receipt but difficulties would emerge if there was dissonance

Divergence/Convergence analysis

Convergence was attained in principled ethics but the divergence lay in the more relational caring ethics and holistic approaches. These were gaps rather than dissonance.

Gaps in philosophical provision	***Match in philosophical provision***
Relational values not realised and holistic values not always attained, particularly when so many professionals are involved and diverse mixtures of approach are experienced, with little continuity	Biomedical ethics seems to match with MND and LC needs

5. ‘STRUGGLE WITH INCREASING LOSS OF CONTROL

This MND category has alignment with the LC category ‘Forced life changes’. The PC category ‘Importance of inter-professional co-operation’ is considered in this triad as it is considered a changing concept for care professionals which is linked to the concept of control. In addition, implications from PC categories ‘Strengths of professional role’ , ‘Role limitations’ ‘Situated friendship’, ‘Learning through experience to care’ and ‘Critical nature of time’ are relevant.

A: Cared For
- need for functional support as their own bodily control diminishes.
- loss of control is a need in itself and so strategies which promote self-control such as active decision-taking and choice are imperative to promote

Divergence/Convergence analysis

Functional support was offered by professional carers with much expertise. Active decision making and choice was promoted in some cases but professionals judged patients abilities on this aspect rather than clearly asking for patient preferences in this area. When a co-ordinated team approach was available inter-professional co-operation flourished e.g. in the nutritional aspect the dietician, speech and language therapist, GP and district nurse were involved. Through having a co-ordinator and case conferences they were able to distinguish their contributions to each other, to the patient and lay carer thus avoiding confusion, duplication and wasted effort for anyone. Lay carers learnt functional support techniques, mainly from professional carers. The LC-MND relationship dictated promotion of choice and self-control approaches.

B: Lay Carers

- acceptance that loss of functional control is inevitable, undesired and uncontrollable
- their work load and responsibilities increase inversely as their partners loss of function increases

Divergence/Convergence analysis

Little support was offered directly to lay carers to come to terms with their partners increasing dependency but much support was offered in terms of teaching lay carers functional skills such as moving and handling techniques and feeding through gastostomy tubes. There was lack of support in terms of their own lives being eroded and need for respite care, particularly in terms of night support. Co-operation between the inter-professional team however, made the organisational aspect for the lay carers lives much more manageable.

C: Professional Carers

- setting up a team of professionals who can help with functional needs removes duplication
- consideration of extra workload of partner who may require their own assessment of need, both physical and psychological

Divergence/Convergence analysis

Functional support met needs of the cared for except where equipment resources were beyond the professional's control. Teams of professionals were not forthcoming and were rare rather than common practice which was viewed as a problem by the cared for and lay carers. Lay carers were not directly supported by professional carers apart from when requesting functional support so the increased roles and responsibilities of lay carers went left unmonitored by professionals.

Gaps in practical provision	*Match in practical provision*
No clear support offered to lay carers	Functional needs addressed
Lack of equipment created practical care problems for patients and professional carers	Active decision making and choice was promoted if patients were judged to want it
Lack of inter-professional co-operation amongst professionals with no clear protocol for setting up teams or case conferences led to confusion and distress for lay carers and patients who did not know who to contact for what functional service	

Philosophical implications

A: Cared For

- As the integrity of the bodily self diminishes, the mental self suffers alongside. These losses are a threat to one's sense of worth and social interaction which may result in isolation, loneliness, frustration and despair
- an other is needed to share these losses with them, to listen, interact and demonstrate to them that they remain Human Beings still and matter as much as when they were fully functional
- need for sensitivity from professionals who are supporting them in physical losses

Divergence/Convergence

Mainly supported in their sense of loss by lay carers but where lay carers did not have the personal resources to deal with this aspect professionals were needed. Professionals attempted relational connection though 'situated friendship' but this relationship was dependent on time available, emotional labour and responsive demeanour which not all professionals were willing or able too offer. No formal counselling made available in any form.

B: Lay Carer

- the struggle also affects them; emotional pressure to increase as they see their partner deteriorate and struggle and they are pulled into the emotional angst as well as exhaustion in offering physical and emotional support

Divergence/Convergence

Limited emotional or moral support offered to the lay carer from professionals. The cared for tried in their ways to support the lay carers. As the speech deteriorated in the cared for, the lay carers became their voice more and this shift opened up the possibility of a 'situated friendship' with the professionals but usually to the detriment of the cared for.

C: Professional Carer

- need for awareness of the holistic loss of 'Being', the threat to the integrity of the self
- need to promote choice and control in planning to support the mental self of the person with MND

Divergence/Convergence

There is no evidence to support professionals as being aware of patients increasing 'loss of Being'. Some evidence from PC category 'learning through experience to care' that patients and lay carers were listened to in this regard but more from the motivated few rather than from all, as the functional role dominated. Sensitivity was evident in the addition or removal of equipment with the acknowledgement that both constituted a further decline in physical powers. A sense of being a team with a united purpose of care was also lacking in the majority of professionals. They tended to respond to individual referrals and work as individuals rather than be co-ordinated by one professional and work together

Gaps in philosophical provision	***Match in philosophical provision***
No real PC connection to the loss of Being experienced by the cared for	'Situated friendship' attempts to maintain a relational focus
No real connection to the physical and emotional stresses the lay carer was enduring to	Learning through practice is an important resource
	learn about people's values and needs
Lack of combined working with other professionals to offer a team approach to care with a common purpose with different areas of expertise	

6. 'TEMPORAL REALISATIONS'

Temporal realisations identified by the MND groups are in parallel to the lay carers 'temporal realisations' and the professional carers appreciation's of the 'critical nature of time'.

A: Cared For

- the realisation of time running out stimulates a rapid assessment of what is important in life to complete before departure
- people with MND need to be supported to remain functional for as long as possible to strive to achieve their stated goals
- spoken goals offers a target for them and others to work towards and re-establish a sense of hope and personal control

Divergence/Convergence Analysis

All three participant groups had a sense of time running out for the people with MND which did stimulate a rapid assessment from their respective functional roles. However, the 'spoken goals' of people with MND did not seem to be heard by the professionals, the idea of having a target to work towards which helped promote a sense of hope and personal control. It was heard by the lay carers who supported their partners to achieve their goals.

B: Lay Carers

- need to expect the possibility of goals being presented to them from their partner.
- goals ideally can be encouraged to be realistic to their possible time frame. (Some goals may have direct effects on their lay carer who may be asked to pursue the goal on their partners behalf if it is not completed before their death)

Divergence/Convergence Analysis

The lay carers awareness of goals in the limited time available was explicit in most cases as the lay carer was so involved in helping their partner reach them or hope for them. When goals involved projected time frames, such as living to the year 2000 (in 1996), or seeing their son graduate, hope was promoted through practical interventions of seeking mobility aids or insertion of an early feeding line. Professionals did not link such actions with patient's goals but linked it to extension of life.

Lay carers identified how lack of organisation amongst the professional carers in terms of the timing of visits did not assist them in planing their day, they did not want to wait around for visits but to know when people were coming

C: Professional Carers

- need for awareness of the possibility of goals being set by patients
- consideration of the pressure the goals may place on the lay carer
- efforts to support the patient to achieve the goals with realisation of the critical nature of time for these people

Divergence/Convergence Analysis

Professionals complained of not enough time to care for patients much beyond their functional responsibilities. Their workloads were high and their appointment time generally low. In addition, ordered equipment was often slow to materialise as there was no 'central resource bank' for quick access.

Gaps in practical provision	*Match in practical provision*
Goals for hope and a sense of personal control was not located by the professionals	Sense of urgency in action
Professionals in not seeing goals could not appreciate lay carers position	Efforts made to support patient's physical functions
Professionals did not have time for care much beyond the functional aspects	
Professionals were hampered in time for gaining vital equipment	
Non-functional care was non-measurable which pressures professionals in this area	
Timing of visits amongst professionals needed better organisation - co-ordinator preferred	

Philosophical aspects of 'Temporal realisations'

The importance of being in time was recognised by all members of the participant groups. This sense of being in time was the driving belief behind their efforts

A: Cared For

- are located in their sense of hope. Achievement of goals or the planning of goals can be the preparatory closure and 'letting go'
- are linked to the process of dying, incorporating shock, anger, bargaining and suffering through impending loss. Such loss is loss of function, self and Being. They are about to lose everything and their goals can serve a gain in this equation.
- are how an interest and support in a person can stimulate goals and hope which may be linked to time span

Divergence/Convergence

The notion of self was underpinned by the concept of hope, the recognition of hope by others and the potential attainment of goals. Within this hope was the preparatory effects of preparing for death, a death almost on their terms as they would try to influence their lives leading to its end. Lack of recognition of their need for hope and associated goals by others was a lack of recognition of their sense of being. Lay carers usually identified with this way of being whereas professionals did not

B: Lay Carers

- taking an interest and supporting their partner can stimulate goals and hope, which may be linked to time span.

Divergence/Convergence

Lay carers and the MND participants were linked through their emotional sensitivity, hope, goals and sense of time. Professionals were aware of the critical nature of time but more in life expectancy rather than achievement of goals. This meant both lay carers and people with MND did not receive a sense of recognition that goals might still be important in time.

C: Professional Carers

- recognition and support for goals as being a vehicle for patients to re-gain a sense of control and hope, which may be linked to time span.

Divergence/Convergence

Most divergence in the professionals under this category lies within the unseen sense hope and goals. Professionals did not seems aware that people with MND and their lay carers may have goals related to their sense of being left in time. This gap left lay carers and people with MND without support in this dimension

Gaps in philosophical provision	*Match in philosophical provision*
The link between the sense of hope and achievements of goals in time	The importance of being in time

7. 'CHANGING RELATIONSHIPS'

This category has a lay carer companion, 'The vulnerability of being a carer' which is immediately relevant as they refer to the changes in relationship between them as a result of the effects of the disease process. Although there is no direct professional category evidence is drawn from the PC category 'Situated friendship' in this analysis.

A: Cared For

- relationships are dynamic at the best of times, they usually involve a give-and-take premise. Where the give reduces in some areas, it may be possible to increase it on others - more thinking strategies rather than doing strategies
- promoting the continuance of previous roles when at all possible reduces the impact of the physical deterioration on the self.
- the loss of ability to fulfil roles eventually means the roles need to continued by someone else: perhaps if this is done in negotiation with the person with MND, it might be a little more manageable for them
- clear transference of responsibilities may offer a relief for the carer and a sense of purpose and worth for the cared for

Divergence/Convergence

The practical reality of MND means that the cared for lose the ability to fulfil their 'normal' role which adds a burden of effort and responsibility onto their spouse. In addition however, the spouse has the added physical effort and responsibility of meeting the physical needs of the cared for. In losing their 'normal' roles and becoming further work for their spouse, the cared for is left with a reduced sense of self worth and an increased level of guilt whereas the carer faces pressure and increased work load with the anxiety of being able to meet the challenges ahead. There is a real sense of divergence from each other in this category which results in changing relationships and the carer being vulnerable themselves to the process. Love seems to be the cement to hold the shift from breaking them up. Without love, or if the shift is perceived as too challenging, then relationships fail. The relationship offered by the professional carers is termed 'situated friendship' where the focus begin on the shift - the effects of the disease process and will end at the client's death without certain adverse long term effects on the professional carer

B: Lay Carers

- As the partners ability to perform role diminishes this places more demands on the carer in household responsibilities which might mean more external help is required and new skills need to be learnt

Divergence/Convergence

Vulnerability would normally be associated with the cared for but the lay carer is also under its influence which leaves two vulnerable people in one household trying to deal with a continual extreme situation. Practically, this exhausts the lay carer and opens the door for the need for additional social intervention. Where such social care may reduce some workload for the lay carer, in contrast it can further stress the cared for by having a new group of 'strangers' practically caring for him or her. So the relational bonds are further challenged

C: Professional Carers

- knowledge of the role and relationships before onset of disease need to be known to appreciate the stressors the person with MND and their partner are undergoing
- changing relationships may affect care delivery by lay carer to spouse and mean more external support is required

Divergence/Convergence

Through a 'situated friendship' professional carers can develop relational interactions at a variety of levels depending on their personal capacity and aspirations and also that of their clients. Both lay carers and the cared for want continuity of carers to be able to know them better and develop trust with them. A constancy of professional carers could act as an anchor in an ever changing relational environment that the lay and cared for are faced with between them. The situated friendship keeps the focus of care on the patient with the professional adapting to the needs of the patient without loss of self. This feature the lay carer cannot match as they are too closely involved with the cared for. A divergent strength for the professionals is this detachment but closeness of a situated friendship.

Gaps in practical provision	*Match in practical provision*
Lack of continuity of carers	Development of 'situated friendship' from PC's
Unequal distribution of responsibility/work effort between LC and MND	Sustenance of love between LC and MND aids physical effort
Vulnerability in LC and MND leaves both open to not coping	

Philosophical implications

A: Cared For
- loss of role is linked with loss of self which changes the dynamic of relationship
- loss of 'self' through altered definition of role is linked with potential loss of life and preparing to leave the relationship through death
- the threat to one's Being as previously defined needs help to remain in the world - the human being could be lost without a valuation of the person who still is
- relationship counselling maybe one route to examining the psychological and emotional interplay in this disease between self, partners and others in the coming into death

Divergence/Convergence

MND participants have a vital need to be accepted and treated as human beings regardless of their physical deterioration. If loss of role is indicative of loss of self then there is immediate divergence in the person known by the lay carer to a dynamic person becoming through illness. This loss of the original self can be equated with the lay carer losing them also and so a relationship change is inevitable. Challenge in communication can further add to the burden on lay carers and create a greater distance between them and their spouse. In terms of the MND-LC relationship, adaptation or learning a new way of being with each other is vital if a relationship is to remain. Remembrance of the past may not be enough to hold a relationship together in such adverse situations.

B: Lay carer
- changing relationships means a new way of being for the lay carer who also has to plan for a future without their partner

Divergence/Convergence

Apart from responding to the needs of their partners, lay carers had to cope with their own changing identifies and sense of being. They received little support from the professionals in this arena. Some lay carers with close relations to their partners received some support from their MND partners

C: Professional Carer

- there seems little awareness of the effects of MND on the sense of self and therefore changing relationships between the LC and MND
- psychotherapy or marriage counselling agencies may be supportive for engaging with the sense of their changing selves and hence their changing relationships

Gaps in philosophical provision	***Match in philosophical provision***
Loss of being is not appreciated by all carers Communication loss does not mean loss of the person Lay carers received little support in their changing sense of being The threat to one's sense of self is not appreciated by care professionals	Love by the lay carer maintains a sense of person-hood with the cared for Emotional labour by carers maintains a sense of understanding the disabled person

8. 'DYNAMIC NORMALITY'

The lay carers also had a sense of a moving normality which they recognised was a 'false normality'. Only one professional carer had an idea of this expressed value which is captured in the PC category of 'Learning through experience to care'.

Practical implications

A: Cared For

- A sense of the 'normal' is related to familiarity to the situation and perhaps an element of feeling slightly in control again
- To help promote a sense of the normal, avoidance of crisis would be supportive
- Maintenance of personal routine as much as possible and when necessary the speedily development of a modified routine

Divergence/Convergence

The need for a sense of the normal within an abnormal context was strong between the cared for and the lay carers. It was achieved mainly between the partners but when a professional acknowledged its existence, it meant that interventions could be kept to a minimum and equipment and lay carer education be focused towards this aim

B: Lay Carers

- awareness of need for a sense of the normal is important
- creating a sense of the normal can only be achieved with the co-operation of the lay carers and family
- close co-operation with their partners and the professional carers to discuss actual and potential problems should support this finding

Divergence/Convergence

Open communication between partners was not imperative in this domain as it seemed there was almost a unspoken need for some relief from the acute pressures which a sense of the 'normal' offered. Explicit communication for this need to professionals was not forthcoming which may have supported the partnerships in its facilitation.

C: Professional Carers

- recognition of this need should support its development
- interventions to support a feeling of safety and relief from immediate danger could be promoted to support this category finding.
- predicting changes in the persons condition should avoid periods of crisis (early feeding tubes, supply of essential equipment) and promote an early return to a sense of normality

Divergence/Convergence

Professionals were acute to the need to maintain a sense of physical functioning for as long as possible in the cared for but did not appreciate the concept of a dynamic or false normality. Appreciation of this concept may have encouraged professionals to be more proactive in their interventions to avoid crises of nutritional, mobility and communication deficits

Gaps in practical provision	*Match in practical provision*
Professional carers did not readily recognise this need to be able to respond to it	LC and MND matched in pursuit of normality together
MND and LC's did not communicate this need to professionals	PC's endeavoured to maintain physical functioning
PC's could have been more proactive in their provision of functional support	

Philosophical implications of 'Dynamic normality'

A: Cared For
- Being 'normal' is valued as a sense of stability, reduction of fear and continuance of life and therefore helpful to create a sense of well-being
- As bodily changes occur, the attitudes others should accommodate such changes rather than look shocked

Divergence/Convergence

Normality is a confirmation of a sense of self within the world, it locates the person in a community which possesses hope, stability and a future. The sense of the normal also needs society to reflect the normality back, so rather than view the disabled person as not normal in their activities, the observer needs to consider the need for the normal and person accordingly. His might not always be a natural stance to action but cognition of the need can influence the being of the other

B: Lay Carers
- promotion of a sense of control for the cared for may support the development of being normal
- knowing the new normality and adapting with it is essential

Divergence/Convergence

The majority of lay carers attempted to instil a sense of control in their partners. This may have been through asking them to prepare a shopping list, asking their views on domestic issues or family decisions. This approach encouraged the cared for to be a normal participating member of family life as they were before MND. Where this behaviour was not encouraged, control was taken from the cared for and invested more in the lay carer. Gaining a sense of the normal then becomes more difficult to attain.

C: Professional Carers

- A calm, confident approach to the family with a measure should assist in this need
- As bodily changes occur, the attitudes of others should accommodate such changes rather than look shocked
- promotion of a sense of control for the cared for may support the development of being normal

Divergence/Convergence

Where a normality need was recognised, promoting choice and personal control, acceptance of the degenerative condition of the cared for and a calm, confident approach was strongly actualised. Professionals who did not appreciate this need were often guided into these ways of being though their ethical stance to practise. However a clear understanding of this cared for value, the need to be normal where possible, may have focused the professionals' sense of purpose in this area

Gaps in philosophical provision	***Match in philosophical provision***
Feeling 'normal' involves a sense of control, as experienced prior to disability. Lack of any control of decision making contribution limits the goal of feeling normal and was evident from LC's and PC's	When control was encouraged a sense of the normality was more readily attained

9. STRENGTHS AND LIMITATIONS OF RECEIVED CARE

All three participant groups have an explicit contribution in this area initially discussed by the cared for. The lay carers specified their experience of strengths and limitations at the professionals. The professionals identified their own strengths and their role limitations. Additionally, the relationship the majority of professionals endeavoured to attain with their clients is included in this section for the discussion, that of a 'situated friendship', which was also a sub-heading in the cared for category.

Practical implications

A: Cared For

- practical interventions through functional support are valued for promoting independence or offering supportive measures
- continuity of professional personnel is a strength as it offers the opportunity for 'knowing' between carer and cared for
- qualities in a carer that are valued are competence, active listening and attentive skills, cheerfulness, trustworthy, instiller of confidence, a sense of being involved with the cared for
- Limited emotional support from professionals can leave the cared for with no emotional care

Divergence/Convergence

Functional support was a convergent strength between all three participant groups although the lack of continuity of the professional personnel was seen as a negative aspect. Limited emotional support was experienced by he cared for from professionals which was considered a criticism and acknowledged as a role limitation of the professionals themselves explained mainly by external factors. The cared for were able to clarify the qualitative criteria they valued in professionals which are equivalent to those identified by the PC's who engaged in 'situated friendship'

B: Lay Carers

- practical functional interventions also assist lay carers in their activities
- continuity of professional carers would also allow lay carer to develop a relationship with them

Divergence/Convergence

Professional functional interventions were seen as a strength by both lay carer and the care for. The interventions supported the lay carers role, particularly when practical knowledge such as ways of moving and handling their partners was taught to the lay carers or clarifying financial support entitlements to buy additional equipment. Continuity of care was not always experienced which was seen as a limitation of professionals and indeed not desired by the PC's themselves. Criteria of positive relationships with professionals were identified which again matched the professionals view of engaging in a 'situated friendship'. There was overall a lack of co-ordination between professionals which most affected the lay carers in terms of organising the day and feeling responsible for managing the situation at home.

C: Professional Carers

- functional care is judged satisfactorily by the cared for but could be rather fragmented
- continuity of personnel is important, particularly as time is often short for the professional carers in their visits
- the amount of emotional support is perceived as minimal which may mean a counselling or psychotherapy professional is needed to help people with MND

Divergence/Convergence

Unmet care needs were focused on economic constraints which reduced the supply of needed equipment or social care personnel, a shortage of time for visits to patients and the absence of a specific neurological specialist practitioner who could advise terminal patients. In addition there was an acknowledged deficit in the emotional care being delivered with the MND family. Professionals were usually very aware of the important role of lay carers and interacted with them as valuable contributors to maintaining the cared for at home.

Gaps in practical provision	*Match in practical provision*
Continuity of caring professionals	Functional support from professionals
Emotional support from PC's to the cared for and lay carers	Situated friendship criteria
	Functional teaching by PC's
Lack of co-ordination amongst the professional 'teams'	Respect by PC's of the LC pivotal role
External PC factors; economic constraints, time constraints on visits, lack of a specific neurological terminal practitioner, lack of emotional care	

Philosophical implications

A: Cared For

- knowing one another in a caring relationship is a vital ingredient of feeling cared for, it instils confidence and trust. Being knowing and knowing the other is central to for the cared for to feel cared for but with the focus mainly on the cared for: 'situated friendship'
- a sense of worth and being valuing is promoting by receiving active listening and attentive listening
- the cared for identify how Being and doing need to inform each other in human interactions
- suffering and loneliness are not addressed by an explicit care professional and expose a value that is unattended in receipt of care

Divergence/Convergence

The clear significance for the compound necessity of practico-philosophical ways of being in care is emphasised through the values exposed by the cared for in this category. When received through a 'situated friendship' approach, this is the desired receipt of 'care' but is unusual rather than commonplace. Although the practical is reported to be satisfied, the philosophical has a huge chasm of need that creates great suffering to the cared for and the lay carers. The lack of sense of knowing professional carers due in the main to their external constraints leaves the MND participants and lay carers with a 'feeling' of not being cared for. Suffering and inner loneliness result which the MND-LC partnership cannot always sustain between themselves as the needs are too great for two vulnerable sufferers to help each other with all the time.

B: Lay Carers

- knowing the professional carers may also enhance their feeling of worth in the caring situation

Divergence/Convergence

When continuity of professional carers is possible who also practise being 'situated friends' in a team approach, there is the greatest sense of being cared for experienced by the MND and LC's. The 'ideals' of the PC's are also drawn to this union of practice-philosophical mode of care approach. The reality is that such practice is rare.

C: Professional Carers

- as suffering and loneliness are not addressed by an explicit care professional, it begs the question of 'can holistic care be possible from the current organisation and role function of care professionals?'
- knowing patients requires a level of involvement with them but with the focus always remaining with the patient - 'situated friendship'
- professionals need support themselves to offer such relationships to clients
- question as to whether professional carers want to go this far in a relationship

Divergence/Convergence

Professional carers are in tension with their ideals and the practical reality. Practical realty is not supportive of emotional interaction with patients as the practical necessities of role predominant and there is little support for professionals who do engage in the emotional aspects of client care. Some professional judgements actually require an engaged knowledge of patients (when to take equipment away, responding to their next physical decline, preparing for death) which if this is lacking leads to significant gaps in care delivery to expectations of care professionals.

Gaps in philosophical provision	*Match in philosophical provision*
Absence of emotional understanding by PC's in terms of PC's being there for them and listening to their suffering	
PC lack unification between the practico-philosophical approach of care delivery- poor holistic care	
Suffering and loneliness is experienced by MND and LC which is not addressed by the PC's	
Lack of 'knowing' of professional carers to facilitate the development of a situated friendship	Match in MND3's team
Lack of emotional support for practitioners who practise their 'ideal' ways of being in care	
Professional judgements require an involved stance in many cases and if lacking leads to significant gaps in care delivery to expectations of care professionals from the cared for and lay carers	

10. 'PREPARING FOR LOSS'

This category is unique to the lay carers. Although the cared for were losing many elements of their existence, including their lives (as realised in their category 'existential shock'), they were the group of people to whom the whole experience was focused on. The professional carers were interacting with the MND and LC's as they were asked to and it was part of their paid work. However, the lay carers were in the unique position of having a future beyond MND, not in the world of paid care work. They had to prepare for the loss of their partner, the loss of their newly acquired cared skills and extra responsibility, the loss of their life as a spouse together with the loss of the professional carers, when their partner died.

The PC category, 'Learning through experience to care' offers some sense of convergence to this need, as those professionals who do learn from patients may well locate this LC need but no reference was made to it by the PC's. In addition, no follow-up care was formally seen as necessary although a couple of professionals did visit the LC's on their own initiative.

Practical perception

A: Lay Carers

- economic concerns meant jobs had to be sustained throughout the periods of illness but at last this would give them a focus after their partner's death, even though it did make their lives very difficult keeping their jobs and being a carer
- no compassionate leave appeared to have been offered to lay carers with the promise of returning to their jobs after the death of their partner
- the need for an potential 'event' seemed high on the agenda for the lay carers once their partner had died, such as travel

Divergence/Convergence

Maintaining paid employment whilst being a principal lay carer was a great stress for lay carers and those who were not employed had the total responsibility for running the household with possible children as well. The lay carer knew these responsibilities would continue after the death of their spouse and although they were made more onerous whilst their partner lived, they would also offer them a sense of purpose when their partner died. These practical tensions were expressed almost as guilt and were offered to me as the researcher but the lay carers expressed their lack of route to take such troubles to. They felt it was rather unseemly to talk about their life after their partner's death. Social carers fulfilled a supportive role not investigated in this study but a role which demands further study in the world of care. Social carers enabled lay carers to continue working though either offering direct care to their spouse or though completing household chores with occasional mix of both. Professional carers did not enter into this aspect of lay carer support apart from t he social worker who could act as the vehicle for organising such social care which had to be paid for by the lay carer.

B: Cared For

- avoidance of the subject may have caused further isolation

Divergence/Convergence

One couple was able to talk to each other in preparing for the MND person's death but it was a sensitive topic which the lay carers were not free in discussing for fear of looking insensitive to the needs of the care for. Although the study cannot suggest it is not usual for couples to prepare for a spouses death, there was not clear professional provision for this future event as there is for cancer patients through Macmillan nurses. Such provision may have supported the family.

C: Professional Carer

- being sensitive to the possibility of opening up a possible conversation in this domain in the partnership may be useful

Divergence/Convergence

A situated friendship with the lay carer may open the door to discussing such a sensitive issue with the lay carer. Awareness of LC's reluctance to do so may also help its initiation by the professional which could be gained though learning through experience to care if the professional considered its a need.

Gaps in practical provision	***Match in practical provision***
Lack of lay carer support to discuss their life after their partner's death, which is fuelled with guilt No professional focuses on the dying aspect of the patient or lay carer so it almost goes unsaid for both spouses	Social carers to take some of the practical responsibility for interventions of daily care

Philosophical aspects

A: Lay Carers

- thinking of your life after your partners death was a stressful process and as it was so sensitive they found there was an absence of anyone to talk this through with. There were notions of guilt talking it through with me. This whole area of thinking about one's being after the death of one's spouse appeared neglected.
- the need to be different again came across from the lay carers in terms of their travel ideas and escaping from the situation that had so entrapped them so long. They would have to create a new way of being
- being together with their spouse in the knowledge that they were to be physically parted was not an easy endeavour - only one couple managed it.

Divergence/Convergence

Lack of a bereavement counsellor to prepare for the death of a spouse was a significant deficit of care for the lay carers. Preparing for a new way of being whilst their spouse was alive gave them a sense of guilt and anxiety but the need was there to consider themselves even whilst they were considering the needs of the partner.

B: Cared For

- Recognition that your partner's life is to continue after your own is a difficult reality. If there is open discussion between partners about the disease and its implications, this might open the way to talk about the surviving partner. This can be seen as a caring act, to talk about the surviving partner and agree some future actions the survivor can take, almost caring beyond the grave. Adoption of this way of being is acknowledged as a challenging route to take

Divergence/Convergence

MND is a terminal disease but the terminal aspects appears neglected. It is treated as an incurable neuro-disablity but does not attract the ways of being that cancer and Aids attracts. The fact that hospice care was not available to MND patients in the Health Authorities area of the study is significant as to how the disease is neglected in the consciousness of professionals and managers.

C: Professional Carers

- Appreciation that the carer who has invested so much time and energy into caring for their ill partner is inevitably 'left behind' and possibly without a purpose highlights the need for follow-up care for the lay person after the death of their partner and even the option for some discussion before the death of their partner

Divergence/Convergence

Follow-up care was only offered if an individual professional carer felt the sense of responsibility due to the development of a situated friendship with the lay carer. Two professionals did action follow-up visits to LC3 when they were received enthusiastically. Other professionals indicated they should but due to time constraints would not.

Gaps in philosophical provision	*Match in philosophical provision*
No professional support for the bereavement process. This support could have continued for the lay carer after the death of their spouse	
Lack of holistic care for the dying, as in the provision of hospice care which focuses on the being of the person through death rather than a person with a biomedical disease	
Lack of a follow-up care protocol reinforces the need for inter-professional co-operation and sensitivity to the emotional needs of the lay carers	Two professionals offered follow-up care through with the lay carers

11. REALITY UNMASKED THROUGH REFLECTION

All participant groups were asked to consider if they had experienced any effects from participating in the guided conversations. Most alignment existed between the cared for and LC's as they both identified that talking had made the situation 'real'.

Practical implications

Cared For
- Talking about their experience can be supportive and assist in clarity of thought
- Talking about their experiences can be distressing and should be stopped if this is the case
- Using strangers reduces their responsibility of affecting someone else with their problems
- Awareness of the effects of talking about their situation may be unknown by the participants before beginning

Philosophical implications

Cared For
- Sharing the burden of 'being-in-extremis' can lighten the burden
- Finding ways of being not realised before discussion can be positive or negative
- Offering a vehicle of talking about their experience confirms their sense of being and making a contribution to others

Divergence/Convergence

The practico-philosophical route is taken in this section as the practically of talking to another at this level is so deeply en-grained with the sense of being heard that they are difficult to separate. It was almost as if MND's and LC's were living a nightmare that they may wake from but as they struggled to survive they blocked out their emotional processes because there was no safe place for it to go. Some participants did not wish to unblock their own safety resource but those that did had no venue for it. The guided conversations were used as a medium for their voice to be heard by themselves as well as another (the researcher) but they also wanted others to gain from their experiences which was part of their motivation to volunteer as a participant in the research. They would have appreciated versions of 'what it was going to be like' living with MND whilst recognising there was no one definitive story. Drawing on the dynamic normality concept, they would have liked to have known how others coped and responded to living with MND, what their realities were in comparison to their own to out-play their own reality. Only short written accounts in the MNDA magazine 'Thumbprint' were available to them or visiting the MNDA meetings which many of them chose not to attend as that experience was considered too raw.

The busy nature of the professional role meant many professionals did not reflect much on the guided conversations about MND. Being busy precludes being thoughtful in depth about one's impact and role with clients. The majority of professionals were not actively supported to practice reflection through supportive approaches of clinical supervision (only the occupational therapist and social workers had fixed supervision sessions). If they identified a need for emotional support they usually turned to their colleagues for informal unplanned support. This dearth of focus and significance of on-going emotional preparation is in contrast to professional bodies promoting continuing professional development for 'fit for practice' where the emphasis remains on functional proficiency. Even though clinical supervision is promoted in professional practice, it remains a mainly a rhetoric with little actual managerial promotion or temporal backing. This gap may well be linked to the gap in professional provision for emotional care for patients and lay carers.

Gaps in care delivery	*Match in care delivery*
No professional with the explicit role to hear their story as it unfolded Little emotional support for professional carers to express and analyse their affective domain in preparation for supporting patients and lay carers in the same domain	MNDA literature to read the stories of others

APPENDIX 15

SUMMARY OF GAPS AND MATCHES IN CARE DELIVERY AND RECEIPT

1. 'EXISTENTIAL SHOCK'

Gaps in practical provision	*Match in practical provision*
Lack of a definitive diagnostic test for MND	diagnoses are offered
Need for learning improvements in 'telling bad news' and following up people who have received it	
Lack of a 'community neurological team' with a lead co-ordinator of professionals	Some teams are organised
Lack of protocol for MNDA literature distribution	This can occur but is haphazard
Absence of specific lay carer support/physical assessment	This can occur but is haphazard

Gaps in philosophical provision	***Match in philosophical provision***
Lack of existential awareness, ontological impact of the diagnostic/existential shock implications for a person/LC	None collectively
Lack of sensitive tellers of diagnosis	
Lack of inter-disciplinary protocol/will to emotionally support the patient/LC through the telling or aftermath of the diagnosis	
Lack of inter-disciplinary co-operation values to offer seamless care	
Lack of emotional support for professionals to help them help others	

2. 'IMPORTANCE OF CREATING MEANING'

Gaps in practical provision	*Match in practical provision*
Adequate instant written information about MND The offer of contact routes to MNDA Lack of experience in care professionals with MND to talk immediate issues over with them	Professional did make efforts to attain written materials to learn about MND

Gaps in philosophical provision	***Match in philosophical provision***
No-one immediately available to talk through the situation and be with the patient and lay carer as follow-up No evidence to identify professionals realised people need to make meaning out of their situation	No clear match

3. 'IDEALS OF CARE'

Gaps in practical provision	***Match in practical provision***
Ethical stance was mainly based on biomedical ethics which led to neglect in more ontological or relational aspects of care	Ethical ideals were in the vision of professionals Respect for humans was a clear motivator for practice

Gaps in philosophical provision	***Match in philosophical provision***
Relational values not realised and holistic values not always attained, particularly when so many professionals are involved and so diverse mixtures of approach are experienced with little continuity	Biomedical ethics seems to match with MND and LC basic needs

4. 'STRUGGLE WITH INCREASING LOSS OF CONTROL'

Gaps in practical provision	*Match in practical provision*
No clear support offered to lay carers Lack of equipment created practical care problems for patients and professional carers Lack of inter-professional co-operation amongst professionals with no clear protocol for setting up teams or case conferences led to confusion and distress for lay carers and patients who did not know who to contact for what functional service	Functional needs were addressed Active decision making and choice was promoted if patients were judged to want it

Gaps in philosophical provision	*Match in philosophical provision*
No real PC connection to the loss of Being experienced by the cared for No real connection to the physical and emotional stresses the lay carer was enduring Lack of combined working with other professionals to offer a team approach to care with a common purpose but different areas of expertise	'Situated friendship' attempts to maintain a relational focus Learning through practice is an important resource to learn about people's values and needs

5. 'TEMPORAL REALISATIONS'

Gaps in practical provision	*Match in practical provision*
Goals for hope and a sense of personal control was not located by the professionals Professionals in not seeing goals could not appreciate lay carers position Professionals did not have time for care much beyond the functional aspects Professionals were hampered in time for gaining vital equipment Non-functional care was non-measurable which pressures professionals in this area Timing of visits amongst professionals needed better organisation - co-ordinator preferred	Sense of urgency in action Efforts made to support patient's physical functions

Gaps in philosophical provision	***Match in philosophical provision***
The link between the sense of hope and achievements of goals in time	The importance of being of goals in time

6. 'LEARNING TO BE CARED FOR'

Gaps in practical provision	***Match in practical provision***
Continuity of carers variable Experienced team of professionals would assist in learning through care	Continuity of carers variable Practical teaching offered to lay carers for skills work

Gaps in philosophical provision	*Match in philosophical provision*
Professional's lack of explicit awareness of the challenge of MND to a person's sense of self. Recognition of vulnerability, loss of control, emotional challenges, shift in one's sense of known being and own learning curve seem absent	
No clear appreciation from carers of link between accepting care and accepting death	
No constancy in relational attempts with clients to understand the effects on their being of their learning curve	Some attempts made in relational learning

7. 'CHANGING RELATIONSHIPS'

Gaps in practical provision	*Match in practical provision*
Lack of continuity of carers	Development of 'situated friendship' from PC's
Unequal distribution of responsibility/work effort between LC and MND	Sustenance of love between LC and MND aids physical effort
Vulnerability in LC and MND leaves both open to not practically coping	

Gaps in philosophical provision	*Match in philosophical provision*
Loss of being is not appreciated of by all carers Communication loss does not mean loss of the person Lay carers received little support in their changing sense of being The threat to one's sense of self is not appreciated by care professionals	Love by the lay carer maintains a sense person-hood with the cared for Emotional labour by carers maintains s sense of understanding the disabled person

8. 'DYNAMIC NORMALITY'

Gaps in practical provision	*Match in practical provision*
Professional carers did not readily recognise this need to be able to respond to it MND and LC's did not communicate this need to professionals PC's could have been more proactive in their provision of functional support	LC and MND matched in pursuit of normality together PC's endeavoured to maintain physical functioning

Gaps in philosophical provision	***Match in philosophical provision***
Feeling 'normal' involves a sense of control as experienced prior to disability. Lack of any control of decision making contribution limits the goal of feeling normal and was evident from LC's and PC's	When control was encouraged a sense of the normality was more readily attained

9. 'STRENGTHS AND LIMITATIONS OF RECEIVED CARE'

Gaps in practical provision	*Match in practical provision*
Continuity of caring professionals	Functional support from professionals
Emotional support from PC's to the cared for and lay carers	Situated friendship criteria
	Functional teaching by PC's
Lack of co-ordination amongst the professional 'teams'	Respect by PC's of the LC pivotal role
External PC factors; economic constraints, time constraints on visits, lack of a specific neurological terminal practitioner, lack of emotional care	

Gaps in philosophical provision	*Match in philosophical provision*
Absence of emotional understanding by PC's in terms of PC's being there for them and listening to their suffering PC lack of unification between the practico-philosophical approach of care delivery- poor holistic care Suffering and loneliness is experienced by MND and LC which is not addressed by the PC's Lack of 'knowing' of professional carers to facilitate the development of a situated friendship Lack of emotional support for practitioners who are motivated to practise their 'ideal' ways of being in care through the practico-philosophical way of being Professional judgements require an involved stance in many cases and if lacking leads to significant gaps in care delivery to expectations of care professionals from the cared for and lay carers	Match in MND3's team

10. 'PREPARING FOR LOSS'

Gaps in practical provision	***Match in practical provision***
Lack of lay carer support to discuss their life after their partner's death which is fuelled with guilt No identified professional to focus on the dying aspect of the patient or lay carer so it almost goes unsaid for both spouses	Social carers to take some of the practical responsibility for interventions of daily care

Gaps in philosophical provision	*Match in philosophical provision*
No professional support for the bereavement process. This support could have continued for the lay carer after the death of their spouse	
Lack of holistic care for the dying, as in the provision of hospice care which focuses on the being of the person through death rather than a person with a biomedical disease	
Lack of a follow-up care protocol reinforces the need for inter-professional co-operation and sensitivity to the emotional needs of the lay carers	Two professionals offered follow-up care through established situated friendship with the lay carers

11. 'REALITY UNMASKED THROUGH REFLECTION'

Practico-philosophical provision ***Gaps in care delivery***	***Match in care delivery***
No professional with the explicit role to hear their story as it unfolded	MNDA literature to read the stories of others
Little emotional support for professional carers to express and analyse their affective domain in preparation for supporting patients and lay carers in the same domain	

APPENDIX 16

LEARNING RECOMMENDATIONS FOR PROFESSIONAL CARERS

1. 'EXISTENTIAL SHOCK'

The practico-philosophical outcomes arising for this category identify:

Functional care is valued by all three groups and standard of delivery and receipt is acceptable
Lack of a specific professional carer to support the lay carer
Lack of education for PC's in telling bad news
Lack of existential awareness of PCs to impact of MND on the cared for
Lack of inter-professional co-operation in care delivery
Lack of emotional support for all three groups

Practical recommendations

- To develop protocols for inter-professional co-operation in care delivery
- To establish and continue emotional support strategies for all three groups, starting with PCs to help the others
- To allocate a PC resource person for specific lay carer support

PC Learning recommendations

The learning needs of professionals are:

1. to learn about the impact of diagnosis on the being of a person to promote a sensitive telling of bad news as well as continuing care. To listen to stories from patients about how they were told their diagnoses and its impact is a useful strategy to illustrate ontological implications. Multidisciplinary workshops (pre and post-registration/qualification) could open discussion and horizons as to the increased positive impact that could be gained from working co-operatively

2. to promote the need for inter-professional co-operation to practice seamless care (including voluntary agencies such as MNDA).

3. to learn about themselves as people, being in the world, and how they can receive support for their ontological needs which would raise their insight and practice abilities to help patients/lay carers.

2. 'IMPORTANCE OF CREATING MEANING'

The practico-philosophical outcomes arising for this category identify:

Inadequate written materials on MND with sources of practico-emotional help
Lack of cognition or sensitivity by PC's to this need in ontological terms
Lack of cumulative experience in community professionals with MND - need for an informed team

Practical recommendations

- PCs to use MNDA literature for newly diagnosed people with MND
- The need to establish neurological teams in the community to service a range of neurological disorders including MND
- Closer co-operation between lay bodies and professional bodies

PC Learning recommendations

The learning needs of professionals are:

1. appreciation of the effects on the cared for of terminal disabling diagnoses to raise their awareness of this stage that families may go though.

2. increased awareness of the role of voluntary agencies to inform PC's and contact being made with them in educational programmes

3. relational education of PC's - what types of relationship the cared for and lay carers want

3. 'IDEAL OF CARE'

The practico-philosophical outcomes arising for this category identify:

There is a match in the principled ethics needs in professional-family interactions
There are gaps in the ontological/relational aspects of care

Practical recommendations

- Maintain a biomedical principle ethical stance as a foundation for professional care activities

PC Learning recommendations

The learning needs of professionals are:

1. Learning biomedical ethical principles to continue as a curriculum requirement for practice.

2. Formal introduction of the caring ethics of Gilligan (1982) and Noddings (1984) in curricula could offer professionals further authority and permission to promote the practice of holistic care as reportedly desired by patients and lay carers.

3. Curricula to include a strong focus on the importance of philosophical approaches to caring and relational values. A legitimate declaration of this knowledge in educational curriculum could make them 'legitimate' and 'respectable' viewpoints and contribute to a stronger ontological emphasis on care.

4. 'STRUGGLE WITH INCREASING LOSS OF CONTROL'

The practico-philosophical outcomes arising for this category identify:

As the patient's struggle with increasing loss of control is an on-going battle until death it demands practical interventions to promote an element of personal bodily control for as long as possible. The diminishing realty of control over one's body and affairs demands a sense of promoting choice and autonomy through ways of caring.

For appreciation of the sense of loss of control requires practitioners to learning about this reality. Learning through practice and through caring for people is the source of this as they offers the opportunity for professionals to appreciate the experiences of others and potentially learn from them to change their practice.

Practical recommendations

- Shift the domination of functional roles to a more balanced view of care incorporating human emotion

PC Learning recommendations

The learning needs of professionals are:

1. About understanding the impact of change demands which people face with disability

2. Learning how to extend their knowledge of patient and carer's values and experiences so professionals can engage more productively with them - read autobiographical accounts of being ill and cared for discussion and opening one's horizons

3. Learning how to support change from the current dominant valuation of functional outcomes over and above emotional care.

5. 'TEMPORAL REALISATIONS'

The practico-philosophical outcomes arising for this category identify:

There are matches concerning the urgency of time for care delivery and receipt but most emphasis is on functional care rather than the emotional and sense of being with another in their short time trajectory. Professionals did not have much time themselves to invest in relational aspects of caring or being with patients or for searching for equipment

Practical/Organisational recommendations

- Time is necessary to develop relationships and needs to be an acknowledged and a permitted use of professional time
- A central store of equipment needs to be established to allow quick access by professional to serve the needs of people with MND
- Identification of a lead professional who can focus on relational aspects of care as a speciality to support patients, lay carers and other professional carers

PC Learning recommendations

The learning needs of professionals are:

1. Time management to offer their limited time to those who need it in the emotional dimension as well as practical interventions
2. More co-operation between professionals in education programmes through earlier shared learning arrangements in undergraduate/pre-registration preparation programmes and continuing professional development
3. Learning about the interface between hope and goals in short time frames due to disease processes to permit PC' to respond to this need in a unified support approach (practically and emotionally)
4. Learning about the impact of a terminal disease on preparing through time for loss and death ad the role PC's can offer in this process

6. LEARNING TO BE CARED FOR

The practico-philosophical outcomes arising for this category identify:

All three groups had the experience of learning but was greatest learning curve was undertaken by the cared for and lay carers. The PC's dimensions of learning was about MND itself and from their patients but the MND and lay carers were learning about receiving, giving and suffering in care. Most gaps were related to an absence of PC engagement in the suffering aspect which led the cared for wanting a greater continuity of carers, a sense of knowing carers and for PC;s to appreciate the effects of MND on a person's sense of self.

Practical/Organisational recommendations

- Develop teams of professional carers whose individuals are mainly experienced in understanding the many effects of living and dying with MMD
- Promote a stable membership of teams throughout care delivery to an individual

PC Learning recommendations

The learning needs of professionals are:

1. Deeper understanding about self identify and the physical-emotional-intellectual challenges faced when under threat and/or duress
2. To learn about the connection in MND to accepting care and accepting one's death
3. To learn that accepting caring is a steep learning curve which the cared for have to engage with
4. To learn how vulnerable lay carers are and the real challenges that face them;
5. To learn to listen more to their clients and to question them sensitively but more deeply as to their concerns and coping strategies

7. CHANGING RELATIONSHIPS

The practico-philosophical outcomes arising for this category identify:

A change in circumstances is followed by a change in relationships as each adjusts to the new situation they are facing. The PC's did not face a change in their relationships but the introduction to new people who they charged with caring for. Most change therefore took place between the cared for and the lay carer although the professional carer had to develop some form of relationship within this dynamic situation

Practical/Organisational recommendations

- As much practical social support needs to be offered as required to allow the cared for and lay carer to have time to adjust to their new roles and for them to have as much time together without worrying about the burden of chores to complete. The continuity of social carers needs attention as these relations are also important
- Availability of counselling or marriage guidance agencies may be helpful in some circumstances

PC Learning recommendations

The learning needs of professionals are:

1. Education to explore the concept of situated friendship, ways of interacting and developing therapeutic relationships with the cared for and lay carer
2. Education to explore the concept of vulnerability, as experienced by the cared for and lay carers
3. Appreciation how both cared for and lay carer are affected by MND and how their relationship can be changed and how best to help in this situation
4. Develop listening skills for both parties with the appreciation that promoting listening and open discussion between the two partners may help their relationship
5. Explore a diversity of communication approaches to facilitate teaching the person with MND and their partner non-verbal communication techniques to permit him/her to continue in a relationship with their spouse

8. DYNAMIC NORMALITY

The practico-philosophical outcomes arising for this category identify:

Both the MND and lay carer participants sought to gain a sense of the normal but this value of normality was overlooked by the majority of professional carers who therefore did not respond to this need

Practical/Organisational recommendations

- Facilitate the ability for professionals to be more proactive in supplying equipment and resources

PC Learning recommendations

The learning needs of professionals are:

1. Educational components to focus on the importance of self-determination and personal control for patients to encourage professionals to facilitate this aspect of care if it is required by patients
2. To understand the need for MND families to search for periods of relative normality for a temporary respite from the acute fear and suffering
3. For professionals to be able to adapt to the changing physical/emotional demands of MND families without surprise

9. 'STRENGTHS AND LIMITATIONS OF RECEIVED CARE'

The practico-philosophical outcomes arising for this category identify:

Strengths and limitations are apparent from all three groups concerning the received care. The main strengths are the functional care delivered and received, the teaching from professional carers and the relational aspect of developing a situated friendship in a few successful cases. These strengths are to be promoted in future care. The limitations were rather more and need addressing through the following practical and PC learning recommendations.

Practical/Organisational recommendations

- Strengthen the profile and importance of emotional care and relational interaction between PC's and their clients to balance this with functional priorities.
- Establish resources for the delivery of clinical supervision or other support mechanism for professional staff to explore and offer 'holistic care'
- Where multi-disciplinary care is practised, make organisational and professional provision for multi-disciplinary support, throgh clinical supervision or other support mechanism
- Develop priorities for the promotion of continuity of professional carers and their co-ordination for the benefit of MND families

PC Learning recommendations

The learning needs of professionals are:

1. Continue developing functional skills with professionals but in tandem with emotional/cognitive understanding for recognition of the ontological aspects of being human as well as the functional aspect to being human
2. To learn about the important factor of knowing another as a essential ingredient of a therapeutic professional-client relationship
3. To learn about the value of listening and being available to hear about suffering rather than having to be action orientated all the time - to learn how hearing another suffering can be therapeutic in itself
4. To understand the complexity and diversity in care - perceptions and experiences of care from experiential and theoretical domains
5. To learn about existential issues in being human - philosophical orientations to what it is to be human and apply these principles to illness, suffering, care and health

10. 'PREPARING FOR LOSS'

The practico-philosophical outcomes arising for this category identify:

The lay carers were preparing for the loss of their partner as well as the loss of the newly acquired insight and skills into caring for another.

Practical/Organisational recommendations

- Need for a specific professional to be allocated to care for the holistic needs of the lay carer - a support person to be there for the lay carer during the life and for a time after the death of their partner (akin to a Macmillan nurse)

- Add a bereavement counsellor to the professional team of carers for people with MND - to allow them to prepare for death if this is a need for them as well supporting the lay carer

- To encourage follow-up care for the bereaved in terms of being able to offer a 'legitimate' health check and a 'social' visit

PC Learning recommendations

The learning needs of professionals are:

1. To learn about the strengths and weaknesses of relationships under duress to understand its dynamics and possible ways to intervene if there is a lack of communication between the two in a serious health situation

2. To have knowledge about the dying and bereavement processes

3. To understand the concept of post traumatic stress syndrome which may be presented by lay carers (or even people with MND following diagnosis) and to know how to seek further intervention of required

11. 'REALITY UNMASKED THROUGH REFLECTION'

The practico-philosophical outcomes arising for this category identify:

Informal reflection is insufficient for learning about experiences whereas a more structured approach through supportive questioning through the format of clinical supervision or equivalent, can more readily stimulate reflection and learning. Time is an important requirement for reflection, also a willingness to be open to learning from experiences. There was little organised reflection for professionals and none for clients. Participants in this study used their guided conversations for their experiences to be heard which highlights a need to be heard and be reflective.

Practical/Organisational recommendations

- Develop opportunities for the cared for, lay carers and professionals to talk about their experiences of caring in order for them to find their voice, have their voice listened to and to possibly develop new learning from their experiences for personal growth
- To allocate a specific amount of time in a professionals work time to facilitate reflection on their practice

PC Learning recommendations

The learning needs of professionals are:

1. To allocate space in their busy agendas to reflect on their practice and interactions with clients in order to develop their practice and to raise their self-awareness and sensitivity to clients
2. To learn how to offer clients the opportunity to reflect on their situations by asking considered questions of how they are coping with their experiences in al its dimensions rather than solely focusing on the physical aspects
3. To actively engage in reflective practice and/or clinical supervision

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