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Younger people's Experience of and Coping with Dementia: a study using Interpretative Phenomenological Analysis

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General Abstract

Dementia research has moved forward in recent years from understanding aetiology and pathology to the development of a psycho-social model to inform understanding of the condition. Younger people with dementia have been much neglected in the empirical field. The available literature on experience and coping with dementia focuses on older people with little available research examining solely the experiences of younger people.

The first part of this thesis is a literature review detailing the current available research relating to the experience and coping styles of people with dementia. Reviewing and reporting this, it goes on to discuss implications and research for younger people who develop the disease.

The second part of this thesis is a qualitative study exploring and developing an understanding of the experience of younger people. Using Interpretative Phenomenlogical Analysis to analyse 6 interviews with people with a diagnosis of young onset dementia the study describes the themes that arise as salient for participants. The paper discusses these findings in the wider literature context, discusses the clinical implications and future research.

Contents

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Literature Review Paper

A review of the literature relating to experience and coping in people with dementia and its relevance to younger people with dementia

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Running Head: Experiencing and Coping with Dementia for Younger People

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Abstract

This literature review critically discusses the current available literature regarding the experience of, and coping with, dementia. Research interest in dementia has grown over recent years. In addition to research into the aetiology and pathology of dementia, attention has turned to the social and psychological factors involved in the dementing process and how services can best support individuals and families affected by the condition. Much of the empirical field includes qualitative accounts of older people in the early stages of dementia. There is very little research focussing only on the experience of younger people with dementia. Models of coping suggest that it is characterised by a careful and ongoing 'balancing act' of 'maintaining and adjusting' (Clare et al. 2005; Clare 2002; Clare 2003) or 'reappraising and reconstructing' (Pearce, Clare & Pistrang 2002). The qualitative literature available is beginning to offer a detailed account of the subjective experience of dementia and is constructing useful models of coping. However, the experiences of those under the age of 65 is still much under recognised and understood and requires further research attention.

Introduction

Dementia is an umbrella term used to describe a global, progressive, chronic condition characterised by deteriorating cognitive functions. This is associated with memory loss, loss of abilities to perform activities of daily living and impaired executive functioning (World Health Organization, 1992). There is no known cure for the disease although in recent years acetylcholinesterase-inhibitors have been recommended for those in the moderate stage of dementia (NICE, 2001).

It is a disease that is generally associated with older age although it is estimated that around 18,319 people in the UK have young or early onset dementia (Harvey, 1998). This estimate is based on those who use services and, therefore, it is likely to be an underestimate with true figures possibly being three times as many. The term 'young' or 'early onset' dementia refers to those with a diagnosis of dementia under the age of 65. The specific needs of younger people with dementia within services have been highlighted recently (Beattie et al. 2004; Braudy-Harris & Keady, 2004). Several specialities are often involved in the care of younger people with dementia and care can often be uncoordinated and variable (Barber, 1997). Older people's services often offer care and many people are under the care of an older person's psychiatrist. However, the needs of younger people are likely to be very different to the older population. Younger people will be more likely to have dependents still living with them, be in full time employment, have larger financial constraints such as a mortgage, be physically well and will likely also have different social tastes and cultural experience than those over the age of 65. The losses associated with losing full time employment and changes in the family dynamic could lead to low self-esteem and depression (Woods, 1999).

This literature review is concerned with the research on the lived experience of dementia and ways in which people cope with the disease. Much of the empirical field includes qualitative accounts of older people in the early stages of dementia. There is very little research focussing only on younger people with dementia. This review will offer a descriptive and critical account of the current literature with reference to areas requiring further research.

Methodological Approach

This literature review has chosen a narrative approach. It was felt that this best supported the available literature and offers a 'story telling' approach to the review of the literature. Searches were made in databases of journal articles such as *PsychoINFO* and *PsyARTICLES* to find relevant literature and resources. The Psychology Specialist working with Older People's special interest group (PSIGE) was also consulted for any relevant literature on dementia in general and specifically related to younger people. Keywords in various conjunctions were used to identify literature these included; dementia, coping, alzheimer's disease, middle age, experience, younger people, early onset dementia, young onset dementia, lived experience of dementia. These searches returned numerous articles which the researcher then examined for relevance by reading the abstract.

Background

Research interest in dementia has grown over recent years. In addition to research into the aetiology and pathology of dementia, attention has turned to the social and psychological factors involved in the dementing process and how services can best support individuals and families affected by the condition. Research has begun to focus on the experience and impact of dementia on an individual's quality of life and caregiver's experiences. Until recently the 'experience of dementia' was not widely acknowledged, and the person with dementia was viewed more as 'to be studied' than capable of facilitating and understanding their experience (Clare, 2008). Kitwood (1997) termed this neglect a 'flight from intersubjective engagement' (p.70). Psychosocial models of dementia have emphasised personhood of the individual with dementia and drawn attention to the concepts of self, identity and emotional experience. This has been reflected in the literature.

Over the years psychological research has often included the opinions and thoughts of those experiencing pathological conditions and those who care for them. Service user involvement in care planning and services is encouraged in line with government directives which states that service users are actively sought out and engaged (Department of Health, 2001). However, the views of people with dementia in service development appears to be much under represented. This is particularly important when some studies have suggested that the view of professionals and carers do not necessarily agree with the individual with dementia (Goldsmith, 1996; Whitlatch, 2001). Wilkinson (2002) emphasises the importance of engaging people with dementia in research.

This is highlighted as being not just important for service development but also that recognising their views is “an ethical and moral underpinning on which dementia research can move forwards” (Wilkinson, 2002; p.20).

In order to investigate the lived experience of dementia and further understand the coping strategies that people employ, many studies have used the subjective accounts of people with dementia. Previous research has shown that people with dementia can offer valuable insights and express their views both individually and as groups (Beattle et al. 2004; Braudy-Harris & Keady, 2004). The need to elicit the views of people with dementia and gain subjective accounts of experience is gaining recognition in the field of research. This growing body of qualitative research offers a rich account of dementia from the perspective of those experiencing it. The aim of much of this research is to direct focus on providing appropriate care as well as treating the disease. Through understanding the experience of dementia authors have hoped that services can improve quality of life.

Gaining insight into the experience of dementia

Much of the current research has focussed on the experience of older people with dementia in the early stages. Few studies have included only younger people and very few studies have included people in the later stages of dementia. Many studies have sought to examine the general experience of dementia but have often focused their investigation on specific aspects of dementia such as coping and adaptation (Clare, 2002; Pearce et al. 2002;

Preston et al. 2007), identity (Harris & Sterin, 1999; Pearce et al. 2002) or the pre-diagnostic phase (Keady & Gilliard 2001).

The Psychosocial Model of Dementia

Fundamental to the topic of the experience of dementia is Tom Kitwood's work during the 1990's. Kitwood (1990), a psycho-gerontologist, pioneered a psychosocial model of dementia in which neurological impairment, uniqueness of the individual and the environment interact to produce the phenomenon of dementia. This presented a challenge as Kitwood pointed out; 'no-one has returned from this particular journey of cognitive impairment to tell us what it is like'. He proposed six access routes to gain insight into the subjective experience of dementia. Firstly, he suggests written accounts of people with dementia. These accounts have highlighted potential feelings that people with dementia can experience such as, 'paralysing fear', sensing a lack of self worth, guilt and frustration (McGowin 1993). Although it is recognised that these accounts are representative of those individuals who are able to articulate their experience in such a powerful way, and during a period in which their cognitive skills are still relatively intact (Kitwood, 1997). The second access route proposed is "gaining insight through listening carefully to accounts of people with dementia in an interview or group context" (Kitwood, 1997, p.15). There are now numerous qualitative accounts giving subjective accounts of dementia in the research arena. These will be discussed in detail later. A third potential access route described by Kitwood is "attending carefully and imaginatively to what people say and do in the course of their ordinary life" (Kitwood, 1997. p.16). This involves looking beyond literal meaning and interpreting and analysing spoken word and action in terms of that individual's experience. This has huge implications for care. Carefully and imaginatively interpreting utterances and behaviours that may not have previously been attached with value would mark a real shift in the way we understand things such as 'challenging behaviour'.

Kitwood's fourth access route involves consulting people who have had dementia-like illnesses. These accounts can give an insight into the experience of loss of memory functioning and confusion. Fifth, Kitwood suggests using poetic imagination to understand this experience. This is something he illustrates personally with contrasting poetic accounts of what he terms 'unattended dementia' and 'person centred care'. Finally, he suggests the use of role play, taking on the part of someone who has dementia and living it out in a simulated care environment. He suggests this has the potential to be both disturbing and enlightening.

Some studies have examined the process of coping with dementia and its experience through consultation with caregivers or observation in a clinical setting (Cottrell & Lein, 1993; Bahron, Silber & Sunderland, 1995). However, as mentioned previously studies have suggested that the opinions of the caregiver differ from that of the person with dementia (Goldsmith, 1996; Whitlatch, 2001).

The experience of dementia

Kitwood (1997) offers a detailed view of the negative experience of dementia. The map is separated into 3 areas; feelings, global states and burnt-out states. He describes 'feelings' as being the subjective states in which emotions are associated with specific meanings, for example, feeling useless due to being unable to complete a previously manageable task. This area is occupied by numerous emotions including various fears, frustrations and anxieties. The middle area of the map is designated 'global states'. This refers to 'raw emotions' associated with a high level of physiological arousal. This area includes emotions such as; terror, misery, rage and chaos. The third area of Kitwood's map contains 'burnt-out' states which occur after the nervous system has been subjected to long periods of high physical arousal.

Kitwood's work has been widely credited and a growing evidence base for the value of psychosocial interventions supports his model. Overviews of psychosocial interventions with people with dementia have substantiated efficacy (Woods, 2003; Cheston, 1998). 'Person centred care' is an initiative that has been widely researched and implemented fundamentally changing our care procedures throughout older peoples services (Bellchambers & Penning, 2007).

As outlined above there may be many ways to gain insight into the experience of dementia. Kitwood's second access route of talking to people with dementia has been adopted by many studies using a qualitative approach through interviews and groups followed by an analysis of the data found to examine this experience. This method seems well suited to gaining a subjective account of dementia (Steeman et al. 2007).

The concepts of acceptance and denial of difficulties are common findings in a number of studies (Keady & Nolan, 1995a; Keady & Nolan, 1995b; Keady, Nolan & Gilliard, 1995). The researchers interviewed people in the early stages of dementia and experiences of fear, anger, frustration, and a sense of losing control were all reported. These early models focussed on a series of stages with different responses such as 'suspecting' and 'covering up' (Keady & Nolan, 1995). This 'covering up' was thought to be a protective strategy for both the person with dementia and their families (Keady, Nolan & Gilliard, 1995). Many of these early findings also suggested a number of positive coping statements and acceptance was common.

Similarly, Steeman et al.'s (2007) study reported an initial positive story from the perspective of older people. Interviewing 20 people with dementia and their families and using grounded theory to explore the data Steeman et al. were presented at first with a positive experience from people, with many reporting only minor problems and stressors. Following deeper analysis the authors felt that a more accurate picture was that people experienced dementia as 'maintaining a constant balance between being valued and being worthless'. In the first phase of their analysis the authors found that participants frequently minimized their memory problems and emphasised their remaining competencies related to knowing, doing, being and self-value. The authors began to question the positive presentation of participants as it did not fit with other literature available (Keady & Gilliard, 2001) or with the reports of family members. However, it should be noted that the participants of this study were diagnosed with 'mild' or 'probable dementia' so it could be possible, at least for some participants, that their difficulties had not yet reached a point that impaired the individuals functioning to a significant level. The authors noted that throughout the interview the participants emphasised positive aspects with 'striking frequency, as if to convince the interviewers' (p.124). The interviewer noted frequent examples of the person's memory problems during interview such as; word finding difficulties, losing track of the conversation, repeating the same stories and difficulties answering abstract questions. The authors report that when confronted with the memory problem during the interview the participant would often reply in a defensive manner, changing the subject or providing an excuse for the memory lapse. In contrast, the family interviewed frequently focussed on their relatives' losses and pointed to changes. For example, one participant described their bike as their 'freedom' whereas her daughter had characterised it as 'aimless riding'. The authors reflected on the interviewers' attitudes towards the person with dementia. They discovered that in the initial interviews the interviewers focussed on the losses associated with dementia and may have resulted in the participants being more guarded in their responses and taking a defensive role. This focus on losses could have been perceived as the interviewer portraying dementia as an 'unacceptable deficit'. They also observed that interviewers did not show genuine sympathy towards the participants. In subsequent interviews the interviewers were instructed to begin by asking about positive aspects of life and show a genuine interest in the participants. This resulted in the participants generating more negative experiences more freely and led to the participant often spontaneously acknowledging their memory problems. The authors concluded that people with dementia are 'active agents' interacting with their illness. Their findings suggest an ongoing struggle to remain feeling of value in the face of the threat posed by dementia. The authors point to the similarity between the experience of living with dementia and that of chronic disease in general. This study also provides a good example of the researchers perspective influencing the outcome of the data and the importance of reflecting upon the cultural attitudes and personal context in which we undertake research.

Coping

Before discussing coping in dementia it is important to have an understanding of how 'coping' is defined. Early definitions of coping described the concept as a cluster of 'intrapsychic processes' through which the individual protects their emotional functioning against external and 'intrapsychic threat' (Haan, 1977). Research moved on to define these as the cognitive and behavioural responses associated with experiencing an external stressor and the behavioural responses employed to avoid the problem within the definition of 'coping' (Lazarus, 1980; Moos, 1976, 1977). Many theories of coping now define the process as using cognitive or behavioural methods to manage internal or external demands (Lazarus & Folkman, 1984; Moos & Shaefer, 1975). A self-regulation model of adjustment to illness proposed by Leventhal, Nerenz and Steele (1984) suggest that the cognitive working model held regarding illness is a major contributory factor to the way in which individuals cope and adjust to their illness, this is termed 'illness representations'. This consists of five dimensions; illness identity, cause, course or time-line, means of curing or controlling the condition and the consequences of the condition (Leventhal et al. 1997). These descriptions of coping may be useful when discussing coping with dementia. The concept of 'illness representations' is relevant to coping with dementia as many studies highlight the individual nature of experiencing dementia and the differences in which this illness is represented to each individual. It is also helpful as 'controlling the condition and the consequences of the condition' may be very specific for someone with dementia as this is as yet an incurable, progressive condition.

Coping with Dementia

In a similar way to chronic or terminal illness, the onset of dementia places major demands on coping resources (Charmaz, 1987). Appraisal of situations and use of resources available to each individual are thought to play a significant role in which coping strategies are used. There are few theorectical models of coping with dementia currently available. Understanding the coping strategies of individuals is critical to further understanding of the psychological experience of dementia and provides an important basis on which to develop appropriate interventions (Clare, 2002). Many studies have used a qualitative approach to this area of research. This often necessitates small sample sizes and has methodological limitations.

Droes (1997) offers a social cognitive perspective of adaptation and coping, emphasising cognitive appraisals as an integral aspect of the model. As every individual has developed resources and assets from previous learned experiences these influence the way in which the individual deals with the changes, challenges and progression of dementia. Droes (1997) suggests that the emotional experience of the individual with dementia will be determined through the cognitive process of appraisal which is based on the person's previous learning and experience. The selection of coping strategies and behaviours are based on the result of this appraisal process. For Hagberg (1997) the coping response is determined by individual factors such as personality, ego-strength, defence-mechanisms and self-concept drawing on psychodynamic factors in coping. This author presents a similar model to Droes (1997), in which the outcome is linked to perception of changes and related to the environmental, cognitive and biological alterations.

Cheston and Bender (1999) discuss the psychosocial model of dementia. They emphasize the importance of the person being seen not in isolation as a 'diseased brain' but as a person existing in a social context. They advocate the concept of 'person-focused' care where the needs of the person with dementia are bought into focus and take into account such aspects; life history, current worries and concerns and the complex interpersonal factors of relationships and roles. Their model of the subjective experience of dementia proposes that dementia is best thought of in terms of an erosive process that affects the individual's sense of security through numerous losses including; cognitive abilities, social roles and opportunities, with the threat of further losses to come.

Six components or phases were identified by Cohen (1991) in the adjustment of dementia including practical coping strategies and emotional reactions.

These included: recognition and concern ('something is wrong' – this is most likely experienced in the pre-diagnosis stage); denial ('not me'); anger, guilt and sadness (why me?); coping ('in order to go on, I must…'); maturation ('living each day until I die'); and finally separation from self. This model gives a description of grieving in which the defence mechanisms are adopted in order to shut out the emotional load of the loss as the pain is thought to be so threatening.

A 'stage-model' is also proposed by Keady and Nolan (1994) including; slipping, suspecting, covering up, revealing, confirming, surviving, disorganisation, decline and death. This grieving process in the cases of an individual without a dementing illness would move through the stage of disorganisation and into 'reorganisation'. However, it is suggested that a person with dementia is unable to move through the final stage because the neurological deterioration leads to them becoming 'stuck' in the stage of disorganisation (Solomon & Szwarbo, 1992). In fact, they suggest that some may not get beyond the stage of denial, possibly a path of least resistance, if individuals are unable to deal with the conflict and stress elicited by dementia's progress.

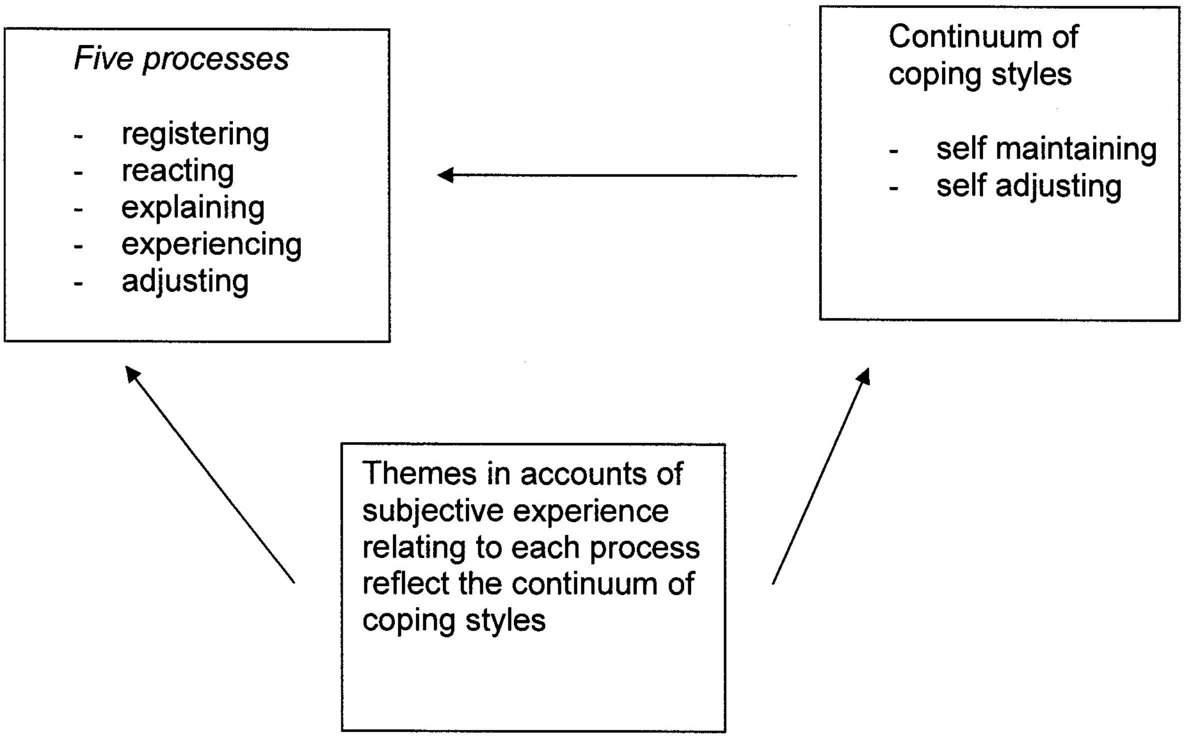
Nolan (1994) suggests that coping is conceived in 3 ways. First, is managing situations by taking direct action. Secondly, managing meaning of situations by creating alternative perceptions is employed. Thirdly, individuals manage symptoms of stress through engaging in activities such as relaxation.

In many ways the stages of coping with dementia are similar to those proposed for managing and coping with grieving. Kubler-Ross (1969) proposed a five stage model of grief including denial, anger, bargaining, depression and finally acceptance. This is further supported by phases described by Murray-Parkes (1986) describing: numbness, searching and yearning, disorganization and despair and reorganisation and recovery.

Moving on from 'staged' approaches

In recent years research has shifted from a staged approach to the experience of dementia and has suggested instead that the experience and coping with dementia is more of an iterative process. As part of an unpublished PhD Clare (2000) presented a model of the psychological experience of dementia in the early stages. The impact of cognitive change is experienced in the context of the person's self-concept, social relationships and networks. Clare suggests that an individual's experience is cyclical, involving five processes; registering the changes, reacting to the changes, trying to explain the changes, experiencing the emotional impact of the changes and attempting to adjust to the changes. This study describes a tension between maintaining prior self-concept and confronting and integrating the changes within the individuals' self-concept. Participants in this research were found to be at different points of this continuum. Expanding on from this Clare (2002) explored this process in more detail. The researcher again suggests a continuum on which participants attempt to adjust and cope in the early stages of the disease. Interviewing twelve participants with early stage Alzheimer's and their partners Clare suggests that strategies employed fell into two groups, ‘self-protective’ to ‘integrative’ responding. Emotional responses, reactions and explanations were characterised by these responses, which represent an ongoing process of adjustment. Themes identified included ‘holding on and compensating’ which were categorised as ‘self protective’ and ‘developing a fighting spirit and coming to terms’ were categorised as being integrative (see figure 1.). The themes in the subjective accounts found by Clare feed into the development of this model and reflect the processes and continuum of coping styles. The integrative responses reflected a balanced struggle with acceptance to integrate the changes occurring within the self. The point of equilibrium is always shifting as the disease itself is changing and progressing. In a follow-up study, Clare, Roth and Pratt (2005) suggest that over time, individuals tend to respond more consistently to either ‘self maintaining’ or ‘self adjusting’. This indicates that style of coping may polarise over time.

Figure 1. Coping styles in the early stages of Alzheimer's Disease (Clare, 2002a; 2003a)



In a similar model Pearce, Clare and Pistrang (2002) describe an ongoing process of maintaining balance. They aimed to explore the appraisals and coping processes of participants and offer a framework for understanding how the participants cope with their illness. Using a sample of 20 male participants, all of whom lived with their spouse between the ages of 60 and 85 years old Pearce et al. (2002) used Interpretative Phenomenological Analysis (IPA) to analyse their interviews. Gender and socio-economic status are thought to influence the coping strategies employed by people (Billings & Moos, 1981; De Ridder, 1995) so this influenced the authors choice to interview a relatively homogenous group. Caregivers were also interviewed to enable triangulation of data. The accounts analysed during this study suggested that the men were involved in an ongoing process of attempting to manage sense of self through a combination of 'maintaining a sense of self' and 'reappraising and reconstructing a sense of self'.

Evidence from both the men and their wives suggested that participants constructed their sense of self from past and present abilities and achievements, and from roles in their relationships and wider social circles. The authors' model suggests a careful balancing act exists between wishing to maintain a prior sense of self against a need to reappraise and construct a new sense of self in the light of changes in cognitive, environmental or social factors. Maintenance of sense of self involved the use of several appraisals and strategies. These appraisals and strategies included: limiting the impact, normalising the memory loss as appropriate with aging, trying a bit harder, take a break, make the most of things, reliance of wife and reliance on medication and services. The model suggests that when these strategies fail or the awareness of limitations and implications of these difficulties occur, the process of 'reappraisal and reconstruction of sense of self begins. Several common themes were identified within this process: loss, change over time, uncertainty, awareness of difference in couple's perceptions, concern for wife, difference, and downgrading expectations. In summary, this study suggests that managing sense of self through dementia is circular, multifaceted, an ongoing process involving a careful balancing act between maintaining, reconstructing and reappraising.

Also aiming to explore living with dementia through first-hand accounts, Gillies (2000) interviewed 20 participants with a diagnosis of dementia. Using a thematic coding scheme, analysis results were reported in two main themes; ‘how dementia is experienced’ and ‘how the participants managed to cope’. ‘How dementia is experienced’ was categorised into a number of sub-themes such as ‘dementia as problem memory’: an age related construct. Some participants had constructed the dementia experience as poor memory consistent with an aging process (this appraisal of memory problems was the most common attribution according to Clare, Goater & Woods, 2006). This has interesting implications when relating theories of coping to younger people with dementia and one wonders whether this coping strategy would be similarly employed for a younger person, perhaps still in full time employment. Minimising or denying the extent of their memory problems were also common findings. Participants’ use of minimisation or denial seemed rooted in an urge to make their failing memory part of a ‘normal’ aging process and therefore offered comfort and reassurance. A second salient theme present within the experience of dementia was a comparison with their former selves or with others. When making comparisons with their former selves it was often to negatively emphasize the detrimental affects of the aging process. Whilst acknowledging that their memory was poorer than in their former selves, comparisons with others were often used to distance themselves from those perceived to be more forgetful or ‘worse off’. Deflated self-esteem due to humiliating public episodes of failing memory were reported. Imagery associated with forgetting reflected use of minimisation when participants referred to their memory as “dicey, dodgy, needing jolted etc” (Gillies 2000. p.370).

In the second theme, 'coping with a failing memory', two principal strategies for coping emerged. A range of practical strategies were employed and a range of emotional coping mechanisms. Practical coping involved using diaries, notes and prompts around the house. Practical coping also involved depending on carers for support, guidance and reassurance. Avoidance was also a practical method of coping, avoiding challenging situations and tasks was reported by participants as a means of reducing the chance of failure. Coping on an emotional level included different strategies ranging from disguising difficulties in an effort to protect fragile self-esteem to resignation and acceptance of their circumstances being beyond their control. The author concludes that the difficulties presented by dementia triggered coping responses similar to those employed by those suffering from chronic illness, namely, serious assaults on the individuals self belief and a striving to lessen the effects through a variety of defence mechanisms.

Preston, Marshall and Bucks (2007) investigated coping in older people with dementia by interviewing 12 people in the early stage of dementia and using Interpretive Phenomenological Analysis (IPA) to identify salient themes. Three themes were identified 'managing identity' and 'making sense of dementia' and 'coping with dementia'. In a reciprocal sense 'coping with dementia' was facilitated by 'managing identity' and 'making sense of dementia'. Two additional themes reflecting the process of coping also emerged; 'conflict and control' and 'context'. The theme of 'managing identity' was described by participants as a challenge but also a way of coping with dementia. Some participants were able to refer to continuity between their past and present self and integrate dementia as part of their present self. Discontinuity between past and present was also identified and lack of integration was demonstrated by description of dementia as highly unfamiliar, traumatic episodes. Denial and minimisation was associated with this lack of integration. Perception of self varied throughout the interviews, with some repeatedly referring to self as able and valued and other times reporting feeling ‘substandard’ expressing themselves as ‘silly, daft or weak’.

The theme of ‘making sense of dementia’ is conceptualised as a motivation to comprehend experiences related to dementia. The process of making sense of dementia as a whole was ongoing, with participants relating it to biological or medical understandings but frequent frustration was reported in trying to reach an explanation that was reasonable to each individual. Making sense of dementia also included difficulties understanding factors such as the onset of dementia and factors that contributed to specific problems. For some a lack of understanding around the experiences associated with dementia resulted in a form of acceptance, however, others expressed puzzlement and a struggle to make sense of ‘strange’ or puzzling experiences.

Coping strategies and mechanisms were identified to include a range of processes. Practical strategies reported included using visual prompts and formal memory techniques and gaining information and advice. Participants also described a logical approach to a difficulty such as pre-planning an activity, retracing steps and using visual cues to aid memory. Cathartic expression such as swearing, shouting and physical exercise were also reported by participants, it is interesting to note that these strategies were limited in their effectiveness by others interpretation of them as negative. Practical strategies such as politely interrupting the other person while they are talking was helpful for the individual to ‘say it while it’s there’. Talking and sharing with friends, family, strangers and professionals were reported to be used in coping in relation to others. As many other studies have highlighted, personal attitudes and approaches to coping or perceiving the difficulty varied. Some participants reported ‘being positive’, ‘looking after myself’, ‘putting problems into perspective’, ‘acceptance vs fighting it’, ‘patience and having faith’ and ‘avoidance vs being open’ were reportedly variations of coping styles.

Preston, Marshall and Buck’s (2007) identification of process themes related to issues of ‘context’ and ‘conflict and control’. ‘Context’ in relation to coping was relevant in that participants acknowledged coping strategies were individual and may not be useful for others, and that use of strategies varied in different circumstances. For example, one participant was open about difficulties in the family setting but wanted to cover up difficulties in a professional context. ‘Conflict and control’ was evidenced by the way that coping strategies varied between each other and even sometimes seemed to be contradictory.

In summary, the authors describe a number of themes emerging from their research, reflecting coping strategies and mechanisms, maintaining self and making sense of dementia and processes of coping such as conflict and control and context. These themes are reciprocally related and although some commonality of experience is noted the emphasis is on the individual differences and contextual factors associated. Individual difference in managing identity and sense of self in the early stages of the disease is something commonly identified in studies of people with dementia.

Younger People with Dementia

The research discussed so far in this review has involved participants of older age and few have included those diagnosed under the age of 65. The views and experiences of those with younger onset dementia are of importance to demonstrate the need for specialist services for younger people and gain knowledge of the subjective experience and coping strategies of a person under the age of 65.

In addition to the social and cultural differences that may present in younger people with dementia there is also evidence to suggest that presentation of dementia and progress of the disease differs from that of the older generation. Some studies have indicated that non-cognitive and behavioural symptoms are more common in younger people (Harvey, 1998; Keady & Nolan, 1997). There is also evidence to suggest that dementia as a syndrome is diverse in younger people and that the disease progresses at a more rapid rate through the stages of the disease (Panegyres & Frencham, 2007; Cox and Keady, 1999).

Group work has suggested that younger people dementia experience a high level of frustration boredom and loss of independence (particularly linked to loss of driving), all contributing to low self esteem and sometimes depression (McNess & Baran, 1996; Fosey & Baker, 1995).

Interviewing 14 younger people with dementia, Beattie et al. (2004) aimed to gain subjective accounts of the participants' experiences of memory problems, their care needs and their views on currently available services. Using textual analysis the authors discuss four emergent themes. 'The experience of dementia' theme was characterised by feelings of frustration reported by participants, particularly in response to others claims they 'know how they feel'. This comment seemed to be perceived as unhelpful by participants. The authors found that there was a level of insightfulness and awareness on behalf of the individuals which was often linked to a sense of being perceived as different and a desire to remain 'ordinary'. People remarked on their desire to be treated as 'normal' people and a sense of being 'invisible' was reported by one individual. 'Diagnosis of dementia'; a second emerging theme was frequently referred to by participants. Time taken to receive a diagnosis, the manner in which it was given, and the uncertainty involved before dementia was confirmed were central issues. Mixed feelings about the assessment process were reported with some feeling that the testing process had been positive, with others being 'baffled' by the process and left feeling under-prepared for the resulting diagnosis. 'The importance of age' was the third theme discussed with the majority of the participants attending specialist day services. Comments from the participants suggested that age appropriate care was of the utmost importance with many feeling that mixing with younger people with memory problems was a positive experience. Care in older peoples' settings, on the other hand, was viewed more negatively. Finally, the issues of risk and danger were reported. Tensions between professionals, carers and the individual were reported about the perceptions of risk and the desire of those with dementia to maintain independence. However this study does not elaborate in depth on their findings, particularly relating to the theme of the 'experience of dementia'.

Braudy-Harris and Keady (2009) focussed on exploring the psychosocial impact of young onset dementia on selfhood of the person with dementia and family carer. The authors highlight the unique and complex nature of the challenges faced by younger people with dementia and the lack of research focussing on this group. Using a qualitative, cross-sectional method the authors aimed to examine what happens to selfhood of younger people diagnosed with dementia and what lessons can be learned from their experiences. The researchers employed interviews with 23 people with young onset dementia in the US and 13 carers in the UK and adopted a grounded theory approach to examine their data. Five themes emerged from their analysis; identity as a worker, identity of abandoned individual, sexual identity, family identity and identity of individual engaged in living. The first theme, identity as a worker, highlights the cultural context in which people interviewed reside. Role and identity is often linked with our occupation in western society and this has repercussions for our sense of self worth and status in society. Loss of occupation therefore has an understandably significant impact on our sense of identity. Identity of abandoned individual was also highlighted as a salient theme in this study. This was highlighted by participants as linked to the significant reduction in their social circle and social isolation. Sexual identity and its relationship to self-image and definition of self was demonstrated by participants. Few studies explore the area of sexuality and dementia but this research highlights its relevance to younger people and their partners. A significant theme in this study was that of family identity. This may include numerous roles held by the younger person with dementia and the diagnosis may bring about a role shift from the specific cultural and societal expectations that may be present. The family context is important to consider particularly when the individual with dementia may be responsible for young dependents needing support. Finally identity of individual engaged in living was found to be an important theme. This is discussed in relevance to the individuals' core values of who they are and the consistency of this remaining throughout the progress of dementia (Harris & Sterin, 1999). This study highlights the importance of numerous factors to be considered for younger people with dementia and their maintenance of self through the progression of this disease.

Studies exclusively examining the experience of younger people with dementia are extremely rare. This may be because the experience is assumed to be comparable to those in older age or due to practical considerations such as rarity of the disease in those under the age of 65, diversity of the disease and the possible quicker progression of the disease in younger people (Panegyres & Frencham, 2007; Cox & Keady, 1999).

Summary

The current research available suggests that living with dementia is an individual experience and the coping processes employed will vary with time, place and person (Preston, Marshall & Bucks 2007). Contrary to former 'staged approaches' to understanding dementia (Keady & Nolan, 1994) models have emerged in recent years that suggest dementia is experienced and coped with as a cyclical process. Integration of dementia seems to be an ongoing process and plays a role in the individual acceptance and processing of the diagnosis. Normalising the difficulties as a normal aging process was a common strategy employed (Gillies, 2000; Preston, Marshall & Bucks, 2007, Clare, Roth & Pratt, 2005). Comparison of self favourably to others less fortunate was also a common finding in many studies (Preston, Marshall & Bucks, 2007).

Models of the coping suggest that it is characterised by a careful and ongoing 'balancing act' of 'maintaining and adjusting' (Clare et al. 2005; Clare 2002; Clare 2003) or 'reappraising and reconstructing' (Pearce et al. 2002).

The qualitative literature available is beginning to offer a detailed knowledge of the subjective experience of dementia and is constructing useful models of coping. However, the experiences of those under the age of 65 is still much under recognised and understood and requires further attention.

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Empirical Paper

Younger People's Experience of and Coping with Dementia: a study using Interpretative Phenomenological Analysis

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Running Head: Experience of and Coping with Dementia for Younger People

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Abstract

The experience and coping styles of younger people with dementia (those under the age of 65) is rarely explored within the existing literature, with much of the relevant empirical data including older people only. Although supported in older peoples services the needs of younger people with dementia may well be different to those of older people and as a group they are often marginalised and under-represented. This study aims to adopt an ideographic approach to exploring and understanding the experience of five younger people with dementia. The five participants were recruited through local older people's Community Mental Health Teams and Interpretative Phenomenological Analysis was used to construct an understanding of their experience. The analysis led to the development of three major themes; loss, relationships and self and identity. Overarching themes of experience and coping were present throughout the data and a number of sub-component themes were further developed and are discussed within this project. The findings of this study are supportive of coping with dementia as a continuum and a constant process of 'maintaining and adjusting' as discussed in previous literature (Clare et al. 2005, Clare 2002; 2003). It also recognises the uniqueness of the experience of dementia and critically discusses the usefulness of age-constructed services. In addition to the current evidence base this research highlights interpersonal relationships and loss of control as key features of the experience of dementia. This project discusses the findings in relation to the existing literature, proposes clinical implications of such findings and suggests possible future research.

Introduction

Dementia, a progressive condition that affects functioning on a global level has been drawing increasing research interest in recent years. Although generally an illness associated with older age it is estimated that around 18,319 people in the UK have young/or early onset dementia (Harvey 1998). This estimate is now over ten years old and based on those who use services and, therefore, it is likely to be an underestimate. The specific needs of younger people with dementia (those under the age of 65) within services have been highlighted recently (Beattie et al. 2004; Braudy-Harris & Keady, 2004). Several specialities are often involved in the care of younger people with dementia and care can be uncoordinated and variable (Barber, 1997). Older people's services often offer care, however, the needs of younger people are likely to be very different to the older population. Younger people will be more likely to have dependents still living with them, be in full time employment, have larger financial constraints such as a mortgage, be physically well and also have different social tastes and cultural experience than those over the age of 65. The losses associated with losing full time employment and changes in the family dynamic could lead to low self-esteem and depression (Woods, 1999). Delivering person centred care for the individual means taking all of this into account and the literature seems to call for specialist services for this group (Beattie et al. 2002). The number of NHS trusts that offer specialist care was just 12 in 1997 and current figures are unknown (Barber, 1997).

Developing an understanding of the way young people cope with and experience dementia is important to enhance the psychological well being of this group of people. Previous research has shown that people with dementia can offer valuable insights and express their views both individually and as groups (Beattle et al. 2004; Braudy-Harris & Keady, 2004). The need to elicit the views of people with dementia and gain subjective accounts of experience is gaining recognition in the field of research and through social and health care organisations. Many now argue that the views of the person with dementia are important to develop assessment services, assess needs and provide service evaluations and outcomes (Alzheimer's Society, 1991; Audit Commission, 2000; Allen, 2001). Involvement in care planning and services is encouraged as a government directive which states that service users are actively sought out and engaged (Department of Health, 2001). However, the views of people with dementia in service development appear to be much under represented. This is particularly important when some studies have suggested that the view of professionals and carers do not necessarily agree with the individual with dementia (Goldsmith, 1996; Whitlatch, 2001). Wilkinson (2002) emphasises the importance of engaging people with dementia in research. This is highlighted as being not just important for service development but also that recognising their views is "an ethical and moral underpinning on which dementia research can move forwards" (p20).

Previous research with younger and older people demonstrates that people with dementia can meaningfully take part in qualitative research and give articulated insights into their experience (Clare 2002; Beattie et al. 2004;

Braudy-Harris & Keady 2004; Preston, Marshall & Bucks 2007). The current research available suggests that living with dementia is a highly individual experience and the coping processes employed will vary with time, place, person and progression of the disease (Cheston & Bender, 1999; Clare, 2002; Preston, Marshall & Bucks, 2007, Steeman et al. 2007). Contrary to former 'staged approaches' to understanding dementia (Keady & Nolan, 1994) models have emerged in recent years that suggest dementia is experienced and coped with as a cyclical process (Clare, 2002; 2003). Integration of dementia seems to be an ongoing process and plays a role in the individual's acceptance and processing of the diagnosis. Normalising the difficulties as a normal aging process was a common strategy employed (Gillies, 2000; Preston, Marshall & Bucks, 2007; Clare, Goater & Woods, 2006; Clare, Roth & Pratt, 2005). Comparison of self favourably to others less fortunate was also a common finding in studies (Gillies, 2000; Preston, Marshall & Bucks, 2007). Models of coping suggest that it is characterised by a careful and ongoing 'balancing act' of 'maintaining and adjusting' (Clare et al. 2005; Clare 2002a; Clare 2003a) or 'reappraising and reconstructing' (Pearce et al. 2002).

The qualitative literature available is beginning to offer a detailed knowledge of the subjective experience of dementia and is constructing useful models of coping. However, the experiences of those younger people under the age of 65 are still much under recognised and require further attention. To date studies that have solely examined the experience of dementia in younger people are rare.

The current study aims to explore and understand in more detail dementia as it is experienced by people who have received a diagnosis of early/young onset dementia. Using Interpretative Phenomenological Analysis, this research aims to give a useful, thorough and high quality account of the subjective experience of six younger people with dementia.

Method

Design

A qualitative design was chosen for this study. This was deemed the most appropriate methodological approach due to this studies' intention of gaining an insight into the subjective experience of younger people with dementia. A qualitative approach can offer a rich and detailed understanding of an individual's experience and has the ability to study a given phenomena which was a central purpose of this research (Silverman, 2006). This method has also been widely used in research with people with dementia and this further highlights the appropriateness of a qualitative approach (Preston, Marshall & Bucks, 2007; Clare, 2002, 2005; Gillies, 2000).

Interpretative Phenomenological Analysis (IPA) was considered the most appropriate qualitative approach for the research question. IPA offers a rigorous, systematic and phenomenologically focussed approach to the interpretation of first-person accounts (Smith & Osborn 2008). This method of analysis is phenomenological: through its attempts to explore subjective experience and 'meaning making' of phenomena, and interpretative: through its acknowledgment of the interactive process of research between participant and researcher and its roots within hermeneutics (Smith, 1996). It is rooted in symbolic interactionism, acknowledging the dynamic nature of research, its social and culturally embedded limitations and the influence of the researcher's own conceptions on the process of research. IPA is widely used throughout a range of disciplines within psychology, particularly within health, social and clinical psychology (Smith & Eatough, 2007). For a detailed rationale of the choice of a qualitative methodology and IPA please see Appendix A.

Participants

Sample size and criteria

The sample of people interviewed in this study were 5 people with a diagnosis of 'young/early onset dementia'; all participants were under the age of 65 when they received their diagnosis. The sample size of this study is in keeping with using an IPA approach. Smith and Eatough (2007) recommend between 6 and 8 participants as an appropriate number as this enables the researcher to hold all cases in mind and make meaningful connections within data. Attempts were made to recruit more participants however due to the time constraints associated with this work and rarity of the disease, only 5 appropriate participants were recruited.

As this study was concerned with the experience of younger people with dementia only those who were diagnosed with young or early onset dementia (under the age of 65 at diagnosis) were recruited. Participants in the early stages of dementia (Mini Mental State Examination score of above 19) were sought to take part. This guideline score was chosen for referrers due to the study intention of using an interview process, meaning the participant would require adequate language skills to take part. It was also part of the inclusion criteria that the person was able to give informed consent to take part in the study, had been referred to their local Community Mental Health Team and was aware of their diagnosis of dementia.

Exclusion criteria included individuals with severe communication difficulties that would make the interview process frustrating for both the individual with dementia and the interviewer[1]. People with co-morbid severe psychiatric disorders were not approached to take part in the study as this may have impacted significantly on their ability to engage in the interview process.

Sample Demographics

The sample of people interviewed included a range of ages from 53 to 64[2] (mean age of 59.2). It included 2 males and 3 females. All of the participants lived at home with their spouse. All participants were of white-British ethnic origin. All participants were diagnosed with dementia when under the age of 65 and were receiving services from specialist young onset dementia groups. MMSE scores ranged from 19 to 28. Four participants had received a diagnosis of Alzheimer's disease and 2 a diagnosis of mixed dementia. All of the participants were prescribed acetylcholinesterase-inhibitors.

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[1] One participant was referred who on meeting with the researcher was not able to give informed consent, or participate in the interview process and was therefore not included in the study. However, this individual and their spouse were thanked for their time and they were keen to be informed of the findings of the study. This will be arranged on completion of this written project.

[2] One participant was referred who was over the age of 65 and his interview was excluded from the analysis. .

Table 1. Brief details of study participants

Name[3]	Age	Diagnosis	MMSE score (out of 30)
Shelia	60	Young onset alzheimer's disease	19
Jean	58	Young onset alzheimer's disease	25
Jackie	61	Early onset mixed dementia	28
Eric	53	Young onset alzheimer's disease	22
Derek	64	Young onset mixed dementia	28

Recruitment

The study was conducted with support from two local Older People's Community Mental Health Teams. Information sheets for both staff (see Appendix B) and potential participants (see Appendix C) were given to the team, and members of the team then acted as gatekeepers for potential participants passing on the details of those who agreed to meet with the researcher. A local group run by the Alzheimer's society for people with young onset dementia was also contacted and agreed to pass on details of the study; however, no participants were recruited in this way. The researcher was also invited to attend a young onset dementia support group to discuss the project and distribute information sheets.

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[3] All names have been changed

Procedure

All 5 participants requested to be interviewed within their own home. Prior to the beginning of interviews the Interviewer spent some time introducing themselves and building rapport. The information sheet was reviewed, and written and verbal consent was obtained prior to tape recording beginning. Following signing of the consent form tape recording began. A debriefing statement (see Appendix D) was given to participants following the interview, this was accompanied by a verbal debriefing and a verbal invitation to receive written feedback when the study was completed. Interviews lasted between 30 minutes and 1hour.

Two of the participants chose to be interviewed with their spouse or family member. The person with dementia was encouraged to provide their account without input from their spouse/family member and any input from the other individual was not included in the analysis of this study.

Semi-structured Interview

The use of semi-structured interviews is recommended when using IPA as an analysis method (Smith & Osborn, 2003). This is because a semi-structured interview offers the opportunity to establish rapport with participants whilst focusing on a particular topic and enabling the participant to tell their own story. The interview schedule (see Appendix E) was drafted following discussion of the aims of the project with supervisors, and reading and researching previous research with similar aims and concerns to the present study. Following invitation from the group, the researcher attended a younger onset dementia group organised by one of the Community Mental Health Teams. The interview questions were piloted here and feedback requested on the value of such a study. The group members felt the study would be a useful process and there was no change to the interview schedule as result of the discussion with this group.

In keeping with the ethos of IPA interviews the interviews were kept informal and flexible and the schedule was designed to be a guide to prompt questioning rather than a restrictive questioning schedule. Interviews allowed the discussion of topics and themes that were not directly related to the experience of dementia. This was felt to be important by the researcher to contribute to the formation of a good relationship and rapport with participants. Clinical interviewing skills were employed throughout the interview process such as active listening and subtle but specific prompts to refocus the direction of the interview. Leading questions were avoided, however, whilst transcribing the first interview the researcher felt that some leading questions were present. This highlighted the usefulness of transcribing after every interview to enable reflection on the interview process and create awareness for future interviews.

Terminology such as ‘Dementia’ or ‘Alzheimer’s’ was not used immediately upon meeting the participant and the lead for which words the participant would like to use for their diagnosis was taken from them. For example, some participants preferred to use the terms ‘memory problems’ or ‘difficulties’.

Any difficulties that the participants had in understanding questions during the interview was promptly recognised by the researcher and every attempt made to aid communication and comprehension through the use of different words or explanations. This shared the responsibility of any communication difficulties between participant and researcher (Preston, Marshall & Bucks, 2007).

Ethical Considerations

Ethical approval was sought and obtained by both the University of Southampton ethics committee (see Appendix F) and the Local NHS Research Ethics Committee (see Appendix G). Both of these processes involved a risk assessment which included thought given to visiting participants in their own homes. Informed consent was a key consideration throughout this study. Formally, participants were asked to give written and verbal consent. Informally, throughout the interview process the participants were reminded that their ongoing participation in the study was voluntary. The information sheet was reviewed at the beginning of every interview before written or verbal consent was obtained. This reminded the participant that they may withdraw their participation from the study at any time and that all material relating to the interview would remain anonymous.

Due to the topics covered in this study there was some degree of emotional risk on behalf of the participants. The subject matter relating to their experiences and coping is sensitive and the possibility of participant distress was considered throughout this research. During the debriefing after the interview process was complete the participant was asked how they had found the interview and if it had raised any worries or concerns. A contingency plan of referral to the care co-ordinator at the local Community Mental Health Team was in place if participants reported concerns or the interviewer became concerned about the participant. No participants reported concerns following interview and the researcher did not feel concerned about the emotional impact of the interviews. Throughout this research the researcher met regularly with supervisors and had frequent opportunity to reflect on any concerns or issues raised for them by the interview process.

Data Management

The transcribed interviews contained no identifying features. The transcribing process was conducted according to guidelines (Silverman, 2006), pauses, breaks in the interview and overlapping comments or interruptions were all recorded in the transcription process. Names used during the interview were not transcribed to maintain the interviewees anonymity. Interview recordings were destroyed following transcription. Hard copies of the interview transcripts were given names (unrelated to the participants' real names) to allow coherent analysis.

Analysis

The analysis process was conducted according to guidelines provided by Smith and Osborn (2003), however, there is no prescriptive approach to analysis. IPA assumes that the researcher wishes to learn about the participants' psychological world, this makes 'meaning' central in the analysis of the interviews. The investigator must engage in a process of interpretation through sustained engagement with the text (Smith and Osborn, 2003).

In order to gain an appropriate understanding of the process of IPA the researcher attended a workshop prior to commencing this project, this gave an excellent grounding in the research process (see Appendix H). Throughout the analysis process consultation with project supervisors, both of whom have an extensive knowledge of working with people with dementia, was undertaken. Peers and researchers experienced in using IPA from the University of Surrey and University of Southampton were also consulted throughout the research process. This gave the researcher an opportunity for reflection, discussion of emerging themes, and discussion of challenges experienced throughout the research. A reflexive diary was kept throughout the research process. IPA recognises that research is a dynamic process and the researchers' conceptions and perspective can affect the research process (Marecek, 2003; Smith & Osborn, 2003). Please see Appendix I for a reflexive account of the researcher's perspective. 'Field notes' were also made after each interview to record any important thoughts (Hale et al, 2007).

Interviews were analysed following a step by step process outlined by Smith and Osborn (2003). Firstly, transcripts were read and re-read, anything that seemed significant or interesting was noted in the left-hand margin. At this stage it was important to become as familiar as possible with the transcript. Reading and re-reading the transcript is an important process as each time the transcript is reviewed it may raise important insights. The next step was to return to the beginning of the transcript and use the right hand margin to note any emerging themes throughout the entire transcript. This is an attempt to capture a higher level of abstraction and use psychological terminology. These themes were then noted on a separate piece of paper. This process was completed individually for each participant. With the emergent themes listed on a piece of paper the next stage was to look for connections between them. The initial list of themes is therefore moved into more analytical and theoretical clusters. At this stage some themes may naturally appear to cluster together whereas others may represent themselves as superordinate concepts (Smith & Osborn, 2003). This process was completed for each transcript, the researcher felt that this was important to maintain the uniqueness and individuality of each participants account (see Appendix J for an analysed account). As the clusters of themes emerged the transcripts were re-read again to ensure that the themes were an accurate representation of the sources account. The lists of clustered themes were then compared across transcripts to find common superordinate themes, and also any differences highlighting the uniqueness of the accounts. Wherever possible themes were titled using the participants own words. The themes that were chosen as the focus for this study were those that emerged through rich passages of the 'individuals account, and those that resulted in a coherent, comprehensive account of the experience of dementia for younger people and the way in which participants coped with this (Smith, 2004).

Validity

The question of validity can present something of a difficulty as the criteria used to assess quantitative methodologies are not appropriate or applicable to qualitative methodologies (Willig, 2001; Yardley, 2000). Yardley (2000) attempts to define principles which can be used flexibly as a guideline to assess the quality of a qualitative project. These include;

1. Sensitivity to context i.e. developing a sophisticated relationship between research findings and the existing literature.
2. Commitment and rigour i.e. prolonged engagement with the topic and developing competence and skill within the methods used and a completeness of data collection and analysis and completeness of the interpretation of the data
3. Transparency and coherence i.e. detailing every aspect of the data collection process and presenting excerpts of textual data.
4. Impact and importance i.e. as with any piece of research it can be judged on its impact and utility in the clinical field.

These principles were examined and considered throughout the process of this study (see Appendix K for a more comprehensive summary of these principles).

As this research's philosophical standpoint maintains that knowledge cannot be objective, and is influenced by the purposes, intentions and experiences of the researcher and is rooted in the social context of the relationship between researcher and participants, inter-rater reliability methods were not thought to offer a meaningful check of the themes developed (Seidel & Kelle, 1995). For the purposes of this study credibility of the themes created was discussed in supervision, the researchers' perspective was fully contemplated and the project was sensitively rooted in the current available literature. This will be discussed further in the discussion section.

To further assess the validity of the themes the researcher has arranged a feedback session with young onset dementia group to feedback the results and gain their views on the findings. Due to time constraints this is not available at present.

Results

Participants' accounts were rich with a wealth of data about living with dementia as a younger person. The individuals interviewed were able to insightfully and coherently describe the challenges they faced and ways in which they coped. Participants talked about the impact of dementia on their everyday lives, relationships and how they have coped since diagnosis. Some coping themes that emerged included practical techniques or strategies whereas others seemed to indicate more of a way of adapting and adjusting their way of life as a means of coping. The themes outlined below are those thought by the researcher to encapsulate the account presented by the individuals interviewed.

Description of Themes

The development of three superordinate themes resulted from the analysis process. These included: *Loss; Relationships*; and *Self/identity*. Each superordinate theme and category can be further divided into sub-theme components as outlined in the table below. Participants' own words have been used to encapsulate the meaning of each sub-component. Throughout the analysis, uniqueness of personal accounts were present as was evidence of balance and conflict. This will be discussed further in relation to each of the themes. Evidence from participants' accounts will be provided for each theme in this section.

Overarching themes of 'experience' and 'coping' emerged as a framework in which the three super-ordinate themes fell. The overarching theme of 'experience' emerged to give an understanding of 'what it is like to have dementia'. It gave the researcher an understanding of how dementia is 'experienced' by the participants in this study. From a psycho-social perspective this means how the persons' emotional and psychological experience is affected by dementia. 'Coping' emerged as the cognitive, behavioural or emotional strategies that the individual employed to 'cope with' the 'experience' of dementia. These themes were felt to contribute to the researcher's understanding of how dementia is coped with as a younger person in this study. Themes relating to 'experience' have been highlighted in bold type and themes thought to be representative of 'coping' are in italics.

Table 2. Overview of Themes

Superordinate Theme	**Component themes**
1. Loss	• **'Probably won't be able to do that with all this'** • **'I want to find out why I'm not allowed to do that'** • *'We've adapted our life'* • *'I thought what I would do is badminton!'*
2. Relationships	• **'I didn't want to lose my old friends'** • **'People like us'** • *'I told them all what was happening'*
3. Self/Identity	• **'I'm no different'** • *'That's it, you've got to adjust and adapt'* • *'I have Alzheimer's'*

It is important to recognise, as many other studies have highlighted, that many of these themes and components overlap and are interconnected. This will be discussed further in relation to each theme, however, many of the quotes used to illustrate themes in this section may also link and support the construction of other themes. Quotes were chosen that the researcher feels best encompasses the theme being discussed.

Loss

This theme represents the numerous different issues raised by participants in relation to loss. The researcher felt the sub-themes worked together as a superordinate theme due to the salience that the participants gave this in their accounts. Dementia was experienced by some as a process outside of the self, affecting the participants' ability to make life decisions and choices, thereby affecting their control of life and resulting in numerous losses. There were also behavioural and cognitive strategies identified that seemed to relate to the participants coping with the experience of loss.

'Probably won't be able to do that with all of this' and *'I want to find out why I'm not allowed to do that'*

Discussion relating to the experience of dementia raised many themes of loss for the participants. Analysis of the transcripts highlighted a sense of being out of control of one's own life either in general or more specifically related to a skill or activity such as work or driving.

"When I found out I wasn't going to be allowed back to school definitely, and I wasn't going to, I had to give up basically. I can't really get another job or anything like that, basically, which I mean, I was always, I've had three careers in my lifetime and I just...I was, I've been teaching for ten years."

(Jean, p2. 164-168)[4]

"I've said to people I'm not going to drive until I know I can drive. Other people don't but I've played by the rules...I wanted everything together so that if they say 'yes you can or no you can't'. When we get to the end of all that then somebody should say yes or no. I hope they say yes."

(Eric, p7. 311-332)

"*(Talking about being told by a doctor he will not go back to work)* We were just setting ourselves up and we had the money we needed and now we

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[4] All participants have been given a pseudonym unrelated to their real name to protect their confidentiality.

haven't got it...She has said I'll probably never work again. I can't believe that's what, no way!"

(Eric, p11. 522-528)

These losses were sometimes related to a specific skill but at other times a general feeling of being out of control. An element of loss was present in many of themes presented here. This highlights the complex nature of experience and the interlinking process ongoing.

'We've adapted our life'

Participants talked about ways in which they coped with the experience of loss and feeling out of control. One of the ways raised was through acceptance and adjustment to/of their life with dementia.

"You have to adapt your lifestyles to the life that you can now live...whatever we can do, we do."

(Shelia, p12. 558-560)

'Staying positive' or 'getting on' were mentioned as ways of coping by a number of the participants. This cognitive strategy of maintaining a positive state of mind was frequently raised by participants.

"You've got to try and be positive about it, I felt well, at least it's not a brain tumour or anything like that, so at least there were positive things to come out of it"

(Jackie, p.4. 154-155.)

"Not to worry because you can't do anything and you can't make it better, and to try and enjoy what you've got"

(Jean, p.9. 403-404)

'I thought what I would do is badminton!'

Another method of coping mentioned was developing new interests and skills. These behavioural techniques were seen as fun but also as therapeutic or a way of 'taking back control' and 'fighting back' against the illness.

"I have been doing belly dancing...Oh it was (*name of doctor)* that suggested it as a way of counteracting the condition, to learn something new...I've always wanted to do belly dancing, I'm hopeless at it mind you, but it's a good laugh!"

(Jackie, p.3. 121-128)

Another behavioural strategy employed to adjust to the losses associated with dementia was that of withdrawing. Some participants reported finding adjustment a difficult step to make and found that restricting their activities was a more appropriate coping mechanism for them.

" When people come round and this and that and the other urm and then I'm in my own environment I'm OK but it's when I'm, when I'm outside"

(Eric, p5. 259-261)

"That's driven me to a bit of quietness, urm, not shy or anything like that just urm...If you think about this, if your indoors...you pull the curtains back in your bedroom and there's nobody around, it's the only way you can sort be like that, yourself, see if you've got an injury or a cold or something like that then you've got an excuse but with this people can't see inside your head so they don't totally understand."

(Derek, p.10. 523-529)

Relationships

Although differences were highlighted between participants in terms of their relationships with others and how these had been affected by dementia it was a common theme raised by all participants. Connected to the theme of relationships was participants' sense of loss and the effect that this had on their sense of self and identity, again illustrating the interconnected nature of these themes.

'I didn't want to lose my old friends'

Some participants felt there had been no change or a positive change since their diagnosis whereas other felt that dementia was having a negative impact on their interpersonal experiences.

"I think that has changed our lives is the social side, we've got a really good social life now"

(Shelia, p.6 293-294)

"(*talking about relationship with wife*) It's like your Mum or Dad saying to you, you grow up, and I didn't realise I was doing anything wrong"

(Derek, p.10. 490-491)

"I didn't want to lose too many of my old friends and I think it does make it awkward because sometimes you remember them and sometimes you might not"

(Derek, p.10. 454-456)

'People like us'

An emerging use of language through the transcripts led to the development of inclusion within an 'in-group'. Many of the participants referred to a group construct when discussing other people with dementia. They used terminology such as 'we' or 'us' when talking about other people with dementia throughout the interview.

"when we get together, we seem to, when I say 'we' I mean other people in the same place as me"

(Jean, p. 8. 358-359)This referral to other people in terms of a group may have been linked to the losses experienced in their previous group and social networks since the onset of dementia.

'I told them what was happening'

Some participants described attempting to hide their difficulties from others whereas other people felt that being open and honest was the best coping method for them.

"I don't tell people when I meet them unless they want to know or urm, I just carry on and try to keep my speech as well as I can you know"

(Jean, p.4. 166-168)

"Our friends have been absolutely great cos when I was diagnosed it was Christmas...and we were due to go to a Christmas party and we both sort of said, well what shall we do? Shall we go? You know. We ended up, we phoned everybody and I told them what was happening and we went, and we had a jolly good party"

(Shelia, p.2. 48-56)

Self/Identity

Many participants remarked on how they have changed since the onset of dementia and the effect this has had on them. Frequently, participants made reference to their former selves and former skills but also often talked about new skills and new roles they had undertaken since the onset of dementia. Individual differences were present within this theme with a great deal of variation between participants sense of self and the impact of dementia.

'I'm no different'

For some participants receiving a diagnosis of dementia did not reflect a change in their perception of self however for others a change in role was of great importance. A new self and new identity was present in some of the participants descriptions of themselves and their roles since the diagnosis of dementia.

"I'm now the one that bakes the cakes"

(Jean, p.8. 368)

"If I hadn't been in this situation I really would have lost out because I now have friends all around me...and that now I'm the person who knows everyone down the road and its just lovely"

(Derek, p.12. 588-589)

The development of a new role and self image indicates that there is departure or a loss of their former self. This was often represented by participants' referral to their former self in the past tense suggesting their recognition of a change in identity and in some cases their struggle with this.

"I've never liked being in the house on my own but I mean before I used to just get on with it"

(Shelia, p.3. 143-144)

"Within the company it used to be if anything needed doing it would be me, here, go do it, and that's that, the fact that I haven't been at work for sometime is a bug."

(Eric, p. 13. 646-648)

'That's it, you've got to adjust and adapt'

One theme of coping and managing the affect of dementia on self and identity was to adapt and adjust to the new role or self identity that emerged. The maintenance of skills seemed to provide some participants with a coping mechanism for maintaining a sense of self and identity.

"Cooking and housework and things, I think my enthusiasm for doing things has gone a bit but it hasn't stopped me doing things like cooking. I always cook from scratch."

(Jackie, p. 6. 274-276)

"(*talking about DIY work around the house*) I've taken some of the floors out and put new ones in"

(Eric, p.2. 92)

"We're no different to what we was yesterday so, we know what the problem is now in fact so we're better off in a way and I can just get on with work and everything"

(Sheila, p.2. 64-67)

"It makes me feel better because urm, well, I know now what I can and cannot do"

(Jean, p.2. 62-63)

Many of the accounts suggested that people found benefit in the pursuit of helping others. This may have given people a positive sense of self and reinforced their feelings of purpose.

"(*talking about taking part in drug trials*) Even if doesn't help myself it might help someone down the line, perhaps in 5 years or something"

(Jackie, p.9. 415-416)

"I know one of the meeting things we had to say urm, I said that I've got Alzheimer's and I know (*name of group facilitator)* said to me "So you've accepted that now" and I felt much better to be saying it and I thought well again perhaps that would help someone else, if you can accept it."

(Shelia, p.13. 616-620)

Linking in with the above themes 'having a purpose' was a commonly reported coping strategy.

"It didn't take me long really, to urm work out that if I was going to carry on urm I'll have to just take it in my stride and just you know, do as much as I can for as long as I can...I decided that I was going to do the best I could, and keep everything going because (*name of husband)* was now the big bread winner and therefore I was going to have to try and take things off him as well. So that's what I've been trying to do."

(Jean, p.3. 141-148)

"I've got plenty of garden and urm, I keep everything up to scratch and I'm renting out a house around the corner to help us with the money now"

(Derek, p.4. 186-188)

'I have Alzheimers'

Integration of dementia with the self and acceptance of the diagnosis was a theme that emerged as salient in the participants' accounts. Some participants readily acknowledged that the disease was part of them whereas others use of language suggested they experienced it as a process apart from self.

"They've given me Alzheimers"

(Jackie, p3. 144)

Despite usually being an illness associated with older people some participants had integrated dementia with self as an age related issue.

"I know it's something you must expect as you get older but it's just, I'd always had such a good memory for things like that, I knew it wasn't right"

(Jackie, p.2. 62-63)

For others this was not possible and dementia was seen as something unexpected, out of the blue and incongruent with their age.

"I couldn't believe it when they told me that I had, *(pause)* I couldn't, I mean I'm 58 and I just don't, I don't, I mean it's for people older than that."

(Jean, p.1. 36-37)

Discussion

This piece of research aimed to give an insight into the phenomenon of dementia as it is experienced and coped with by five younger people. It aimed to explore and understand participants' experience and meaning making of having dementia as a younger person. It found common themes and similarities between the participants' accounts but also highlights the different experiences and coping strategies employed. This study indicates that although there may be commonalities in the experience and ways of coping with dementia it is essentiality a unique experience. The themes that emerged from the study highlighted both experience and coping and suggest that the way in which dementia is experienced may mediate the coping strategies employed. For example one individual who had felt that having dementia had had no detrimental affects on her sense of self was keen to be open and honest with friends about her illness. For another individual who felt keenly the loss of her work and role through dementia hiding her dementia was a more appropriate way of coping.

There may be numerous factors associated with how dementia is experienced and then how it is coped with. For example, a person who experiences a sense of loss of control as they are affected by dementia may cope with this by adjusting to the limitations imposed by dementia and adapting their lifestyle, or they may find this a challenge and begin to withdraw from others, activities and former lifestyle in an attempt to manage the unpleasant experience of not being in control. The reasons for these differences in coping and experiences are not explored within this study but they may be linked to personality, environment, relationships or any number of psycho-social factors.

Summary of Findings

This study identifies numerous themes associated with the experience and coping strategies employed by five people with a diagnosis of young onset dementia. Overarching themes of 'experience' and 'coping' were present throughout accounts. Three super-ordinate themes were identified; *Loss, Relationships, Self/identity.* These themes were comprised of numerous subcomponents but were strongly interlinked and overlapping. Individual differences were strongly present throughout the transcripts.

Although these themes have been developed and presented as components to produce a coherent account of living with dementia as a younger person, it is important to recognise that these themes are intrinsically linked and interactive. For example, it is difficult to separate the experience of a change in relationships with others without it having an impact on self and identity. Similarly, the use of a coping mechanism such as 'withdrawal' may be self protective in terms of it providing people with a non-challenging means of avoiding situations that may have a potentially threatening impact on sense of self. However, the choice of withdrawal is likely to have some impact on the individuals' sense of self as the person will no longer have an opportunity to receive evaluation through interaction with others. It is better to consider the themes described in this study as reciprocal processes that are interrelated and not as individual constructs. It is also evident from the accounts given that different strategies and experiences are described by individuals at different times and they are not mutually exclusive. For example, an individual may attempt to maintain their skills whilst at the same time adjusting and accepting a change in role, one does not preclude the other.

As this study was concerned with the clinical implications of experiencing and coping with dementia as a younger person, it may have been possible to organise the themes differently focussing more on the cognitive, behavioural and emotional components of the individuals' experience. However, if organised in this way it may have been detrimental to the more general concepts of experience. By adopting a much more flexible focus for themes to emerge and the accounts of the individuals to decide the construction of the account the philosophical stance of this project has been closely adhered to. The way this study has been conducted allows the richness of the data to be reflected.

Previous Research on the Experience and Coping with Dementia

Kitwood's work on experiencing and coping with dementia highlights the individual nature of this process. This would fit well with the findings of this study which demonstrated the shared experiences of people but also highlighted the variation present in each individual. The overarching theme of 'experience' can be linked to Kitwood's (1997) suggestion of the three states existing in dementia; feeling, global states and burnt out states. The 'feelings' mentioned in Kitwood's work refer to the subjective states in which emotions are associated with specific meanings, in the context of this study this could be related to the participants reported feeling 'loss of control' or feeling shock and disbelief at their diagnosis. The concept of balancing and maintaining, with individuals using different strategies at different times is a common finding in studies of coping (Preston, Marshall & Bucks 2007; Clare 2002; Pearce, Clare & Pistrang, 2002). Clare et al. 2005 suggests that coping with dementia is best conceptualised as a continuum with an ongoing balancing act of managing and maintaining sense of self. Where one is at on that continuum may depend on numerous factors such as personality, stage of dementia, environment contextual factors such as family support. It may also be related to the impact that dementia has on their lives. For example some of the participants interviewed in this study had retired from work prior to the diagnosis of dementia, or had voluntarily given up driving before any cognitive impairment was present. This may make the impact of cognitive deterioration and a diagnosis of dementia a very different experience to someone who was in the midst of a career.

Some of themes highlighted in this study are similar to those found in previous research. The theme of 'withdrawal' described here is comparable to that of avoidance found in previous accounts (Clare, 2002a; Gillies, 2000; Preston, Marshall & Bucks, 2007, Pearce , Clare & Pistrang, 2002). Both themes suggest an element of passive reluctance to engage with perceived threatening experiences or situations. However it is important not to label individuals' coping preferences as positive or negative. For an individual who avoids or withdraws it may be the most appropriate coping mechanism with the personal and environmental resources available to them. Focusing on the positives was another theme highlighted by this study and previous studies exploring coping (Pearce, Clare & Pistrang, 2002; Clare 2002). This may reflect a cultural trend in this society or cohort to make the best of things or not to 'grumble'.

Loss is a common theme in previous research with some researchers characterising dementia as a process of losses (Cheston & Bender, 1999). The importance of interpersonal factors has also been raised in previous research with the complexities of relationships and roles being of particular importance (Braudy-Harris & Keady, 2009). As authors have highlighted previously the person with dementia exists within a social context therefore it is unsurprising that sense of self and relationships are a salient theme (Cheston & Bender, 1999).

Limitations and Methodological Issues

As acknowledged by using an IPA methodology the research conducted here has been a subjective account, and reflects only the experience of the people interviewed as interpreted by the researcher, and also reflects the 'researchers biases and assumptions. Therefore the intention of this study was not to produce generalisable findings to a wider clinical population. However, it gives useful and thought provoking evidence regarding the experience of dementia and the ways in which younger people may cope with this. It has highlighted the individuality of each individual's experience. This study has used a small sample size in keeping with the methodology chosen. It is also worth noting that all participants in this study lived with their spouse and had access to support through local services, this is likely to have implications for the type of coping mechanisms that the individuals interviewed would use. There is therefore an obvious bias in the selection procedure of this study to recruit through services such as a mental health team. Themes may have differed significantly if the interviews were conducted with participants living alone without access to supportive services. It is also important to consider that those who chose to take part in such a study are likely to be happy to talk about their experiences of dementia in detail with a stranger. This may indicate that these individuals have a sufficient degree of acceptance and therefore their thoughts and feelings on the subject may not be representative of other people with dementia.

Important factors to consider also is the early stage at which the participants were experiencing dementia. There is very little research exploring experience in people in the later stages of dementia and it is difficult due to the effect of the disease on expressive and comprehensive language abilities to suggest how this might be achieved. However it is important that this is given thought for future research.

This study has successfully fulfilled its research aims to explore subjective accounts, however, it may have been beneficial for this study to include the views of carers and professionals to provide triangulation of data. This has been used in previous research of this type and can be useful.

There are potential limitations to using interview methods as a means of accessing subjective accounts. One possible limitation which is important to consider is that this kind of approach accesses only conscious information as it relies on the first hand account of the participants. It is therefore possible that there are numerous unconscious processes ongoing that either the individual is unable to access or unwilling to share in an open interview process.

Cultural and Societal Issues

This study reflects the particular culture in which both the researcher and the participants reside. The thought process behind interviewing younger people with dementia is due to the potential different needs and experiences of such a group. It is possible that the construct of being a younger person, under 65, is in fact arbitrary. As societies views on working age change and an increase in retirement age may be likely, there may be changes in the social constructions of what is 'older' and what is 'younger'. The individual differences highlighted in this study suggest that the different methods of coping and experiencing dementia may be more linked to stage in life and environmental context as opposed to age per se. Furthermore, some studies have suggested that it is not age specific services that younger people most value but services that offer a person centred approach paying close attention to the individuals needs (Reed et al. 2002).

The people interviewed were all of white-british ethnic origin as is the researcher conducting this study. This will have implications for the findings as the results may reflect culturally embedded methods of coping and ways of experiencing progressive illness.

Relevance to Clinical Field

This project has been able to contribute a qualitative account of living with dementia for younger people. The methodology used in this project is highly compatible with clinical psychology and offers a unique insight into the subjective experience of the participants. This project was concerned with the individual experiences of its participants, and the process by which this is achieved can be considered similar to the building of the therapeutic relationship that a clinical psychologist would aim to create with a client (Yardley, 2000). The interview process in this study acknowledges the importance of building rapport and relationships with the client, it also emphasises the influence of the individual researcher, and encourages reflexivity. These processes are comparable with those involved when forming a therapeutic relationship. Therefore the findings of this study have been achieved through methods that are in many ways appropriate and paralleled in clinical practice. This person centred approach to research highlights the unique experience of the individuals who participated, and is well fitting within the current climate of clinical psychology.

Clinical Implications

The themes identified here have many important potential clinical implications. One such implication is the impact of dementia on the individuals' relationships with others. Research suggests that people with dementia may be at high risk of developing depression and anxiety compared to people without dementia (Woods, 1999). The current clinical evidence base for therapeutic work with people with dementia suggests many approaches that involve individual work with the person with dementia. The National Institute for Clinical Excellence guidelines (NICE, 2001) recommend individual cognitive-behavioural therapy as a treatment of choice for people with dementia with anxiety and depression. This study suggests the way people experience and cope with dementia may be closely linked to their relationships with others, their experience of loss and the impact this has on their sense of self and identity. At present there is little empirical research examining the efficacy of working systemically with people with dementia and co-morbid mental health problems. If the experience of dementia is closely linked to interpersonal relations then it may be beneficial for treatments for people with dementia to include relationships as an essential feature of any intervention. The themes highlighted in this study also suggest people with dementia may feel a significant loss of control over events in their lives. As professionals it would be important for us to consider this and attempt to empower and not underestimate younger people, ensuring that we engage them in decision making processes and maintain a sense of control. It also highlights the importance of life-stage and lifestyle not just the age of the individual being relevant. This raises important considerations for people transitioning from working age adult services into older people's services. As professionals it is important that we consider people's life-stage, individual experience and empowering people while they experience the losses associated with dementia.

Future Research

Future research may further our understanding of experience and coping in younger people particularly with relevance to the factors that mediate difference in experience and coping. Personality, attachment style, environment, family context and life stage may all play an important role in these processes.

This study represents the experiences of participants in just one point in time and in future research it may be helpful to adopt a longitudinal methodology to explore the changing processes and patterns as the disease progresses.

Wider Research Context

This research has highlighted the experience of loss of control as salient to the experience of dementia for the younger people interviewed. To this researcher's knowledge this has not been highlighted in previous studies of dementia. Control and chronic illness is a topic that has received much attention and the effect of dementia on locus of control may be of interest for future research. Health psychology research has shown a keen interest in locus of control and its relationship to coping with chronic illness and this may be a useful topic for future research.

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List of Appendices

Appendix A

Rationale for Methodological Choice

There were numerous reasons that a qualitative study using IPA was chosen for this research; these will be outlined below:

1. Firstly, the aim of this research was to explore the experience and coping of younger people with dementia. This area is currently larger under researched with very little available literature present looking specifically at this topic for younger people. Therefore this study was required to be exploratory as research in this field was in its infancy. The use of measures examining coping or experience was not appropriate as no standardised or validated measures of this type exist and the detail and richness of the account would not have been maintained if such measures were available.
2. The constructs of experience and coping lend themselves much more to explored using qualitative analysis. They are processes underpinned by personal and unique experiences.
3. IPA was thought to be the most appropriate method analysis as its key features are highly compatible with psychological models and theory. This ideographic approach began with analysing each individual account in its entirety thereby retaining the uniqueness of the individuals' transcript before making links and interpretations across transcripts. The themes emerged as a result of this in-depth analysis and led to the formulation of a hierarchical construct of the themes. This method felt very compatible with clinical psychology for the researcher and in many ways reflected the process of formulation by

which clinical psychologists hypothesise and develop theories collaboratively with clients in a therapeutic context.

4. Alternative qualitative approaches were considered and deemed inappropriate for the aims of this study. Grounded theory was one such considered approach and although this may have been an efficient means of conducting this project it was felt IPA more overtly and specifically related to the psychological experience of the participants. IPA has also been described as specifically relevant when attempting to gain insight into the lived experience of illness. Both content analysis and discourse analysis were thought inappropriate for this study as neither specifically focus attention of the experience of the phenomenon they study.

Appendix B

Information sheet for staff

Staff Information sheet

A Qualitative Study of the experiences of Younger people with Dementia

I am a Trainee Clinical Psychologist at Southampton University. I am doing a study with Ann Marshall, Clinical Psychologist at Newtown House. We are trying to get a good understanding of the experience of dementia and ways people find to cope.

Taking part in the study would mean the individual talking to me about their experiences and the challenges they have faced. We would be talking for around one hour or more but they can conclude our discussion at any time wish. Our discussion can take place at Newtown House or at the patients home if they would prefer. Any travel costs in getting to see me will be reimbursed.

I will tape record and then transcribe our discussion. Tapes will be destroyed when the study is completed. Names and any details about the individual will not be identifiable on the tape.

People are welcome to bring a friend or family member to the interview if they would prefer, it may be good for them to have someone with them to talk to after our interview.

I will analyse the interviews using an analysis technique to find common themes about people's experiences and the ways in which people cope with challenges they face. It is hoped that improving our understanding of the experience will improve that ways in which we offer people care and support.

They can withdraw their consent to take part in the study at any time. If they decide to take part in the study they will be invited to a feedback session in which I can report back my findings and answer any questions they have.

This study is covered by the University of Southampton's Insurance and Indemnity policy.

If you know of anyone who would be interested in taking part please contact Ann Marshall at Newtown House.

If you have any questions please contact me, Emma Hines, at 34 Bassett Crescent East, Highfield Campus, University of Southampton, Southampton, SO17 1BJ. Tel: 02380595321. Or Ann Marshall at Newtown House, 2a/b Newtown Rd, Eastleigh, SO50 9DB. Tel: 02380620162.

If you have questions about their rights as a participant in this study, or if you feel that they have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 5578.

Appendix C

Information sheet for participants

Participant Information sheet
A Qualitative Study of the experiences of Younger people with Dementia

I am a Trainee Clinical Psychologist at Southampton University. I am working with the Eastleigh Older People's Community Team asking people under the age of 65 with young onset dementia to take part in my study. We are trying to get a good understanding of your experience of dementia.

Taking part in the study would mean talking to me about your experiences and the challenges you have faced. We would be talking for around one hour or more but you can conclude our discussion at any time you wish. Our discussion will take place either at the Older People Community Team at Newtown House, Newtown Rd, Eastleigh or I can come to your home if you would prefer. Any travel costs in getting to see me will be reimbursed.

I will tape record and then transcribe our discussion. Tapes will be destroyed when the study is completed. Your name or any details about you will not be identifiable on the tape.

You are welcome to bring a friend or family member to the interview if you would prefer, it may be good for you to have someone with you to talk to after our interview.

I will analyse our interview along with interviews held with other people with young onset dementia. I will use an analysis technique to find common themes about people's experiences and the ways in which people cope with challenges they face. It is hoped that improving our understanding of your experience will improve that ways in which we offer people care and support.

Participation in this study is completely voluntary. It does not affect your care in anyway whether you decide to take part or not. You can withdraw your participation at any time.

If you are interested in taking part in this study please let your care co-ordinator know or whoever gave you this information sheet. Alternatively you can contact Ann Marshall at Newtown House on: 02380620162.

If you decide to take part in the study you will be invited to a feedback session in which I can report back my findings and answer any questions you have. For any questions please contact me, Emma Hines, at 34 Bassett Crescent East, Highfield Campus, University of Southampton, Southampton, SO17 1BJ. Tel: 02380595321.

If you have questions about your rights as a participant in this study, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 5578. This study is covered by the University of Southampton's Insurance and Indemnity policy.

Appendix D

Consent and Debriefing Statement

Participant Consent Form

A Qualitative Study of the experiences of Younger people with Dementia

Statement of Consent
I ______________________________ have read and understand the participant information sheet.

I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that data collected as part of this research project will be treated confidentially, and that published results of this research project will maintain my confidentially. In signing this consent letter, I am not waiving my legal claims, rights, or remedies. A copy of this consent letter will be offered to me.
(Circle Yes or No)
I give consent to participate in the above study Yes No

I give consent to be audiotaped Yes No

I understand that these audiotapes will be destroyed after analysis Yes No
Signature......................... Date..............
Name...

Debriefing Statement

The aim of this research was to gain a better understanding of the needs of younger people with dementia. It is hoped this will help us to direct service provision in the future, highlight areas of unmet need and provide better psychological care. Once again results of this study will not include your name or any other identifying characteristics. The research did not use deception. You will invited to discuss the findings of this study when the results are available which should be some time early in 2010.
If you have any further questions please contact me Emma Hines at Clinical Psychology, 34 Bassett Crescent East, Southampton University, SO17 1BJ.
Thank you for your participation in this research.

Signature ______________________________ Date

____

Name

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ.
Phone: (023) 8059 5578.

Appendix E

Interview Schedule

The interview aims to be open ended and flexible according to the suggested structure in IPA (Smith, 2004). Some example questions may be:

"What have the last few months/years been like for you?"

"Has there been anything you have found difficult to cope with?"

"Can you tell me about good days and bad days?"

"What do you feel your needs are at the moment?"

"Do you think you've been able to manage your needs?"

It is not possible to give a completed manuscript as the interview questions are intended to be flexible. Prompts to the ones stated above will be used. For example;

"How did you cope with that?"

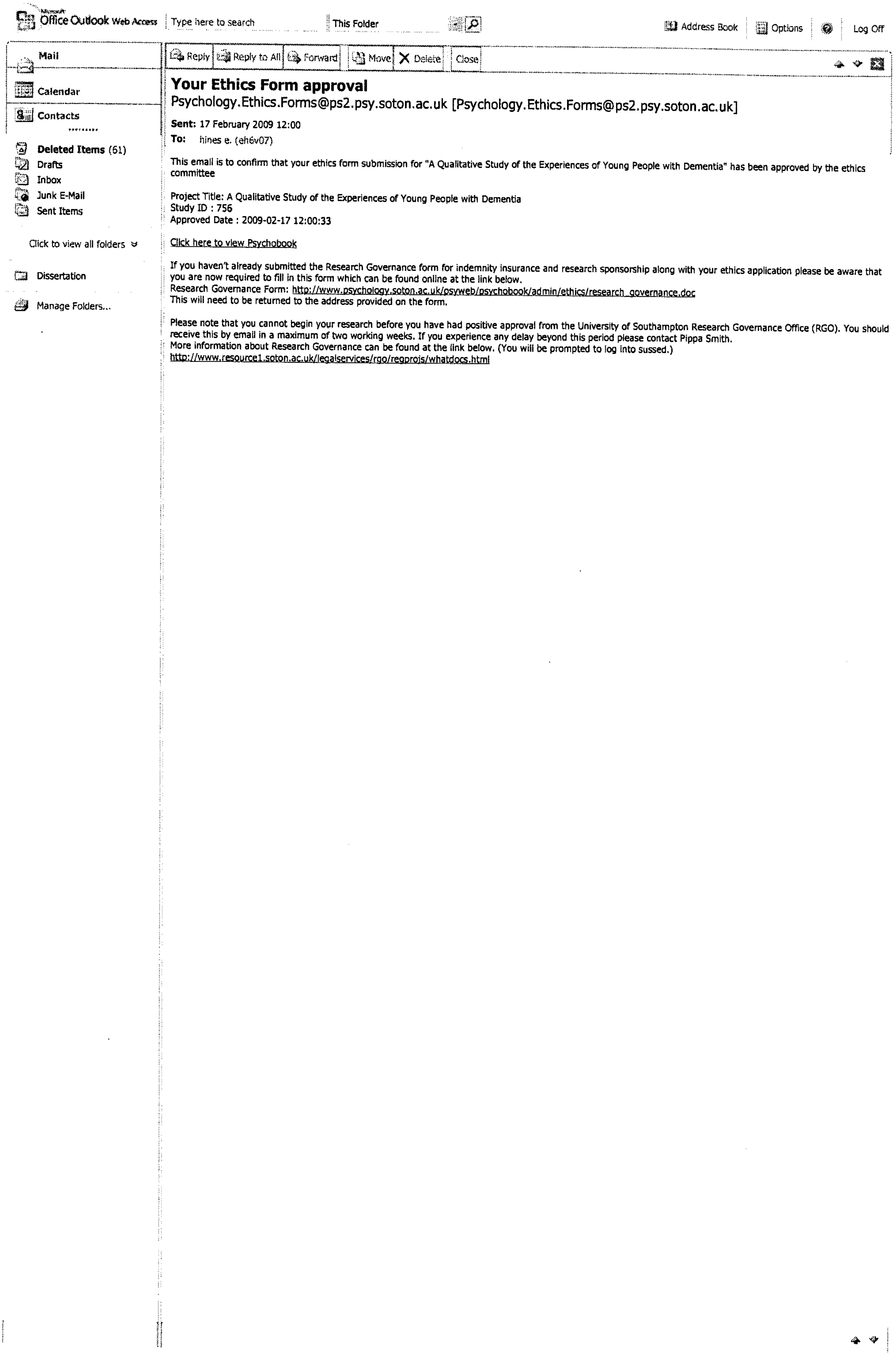
"What did you find helpful/unhelpful during that time?"

"Tell me a bit more about that"

Questions may need to be communicated several times in different ways to ensure that the person is able to understand what is being asked. Prompts and reflections will also be used to explore topics further.

Appendix F

University of Southampton Ethics Approval



Your Ethics Form approval

Psychology.Ethics.Forms@ps2.psy.soton.ac.uk [Psychology.Ethics.Forms@ps2.psy.soton.ac.uk]

Sent: 17 February 2009 12:00

To: hines e. (eh6v07)

This email is to confirm that your ethics form submission for "A Qualitative Study of the Experiences of Young People with Dementia" has been approved by the ethics committee

Project Title: A Qualitative Study of the Experiences of Young People with Dementia
Study ID : 756
Approved Date : 2009-02-17 12:00:33

Click here to view Psychobook

If you haven't already submitted the Research Governance form for indemnity insurance and research sponsorship along with your ethics application please be aware that you are now required to fill in this form which can be found online at the link below.
Research Governance Form: http://www.psychology.soton.ac.uk/psyweb/psychobook/admin/ethics/research_governance.doc
This will need to be returned to the address provided on the form.

Please note that you cannot begin your research before you have had positive approval from the University of Southampton Research Governance Office (RGO). You should receive this by email in a maximum of two working weeks. If you experience any delay beyond this period please contact Pippa Smith.
More information about Research Governance can be found at the link below. (You will be prompted to log into sussed.)
http://www.resource1.soton.ac.uk/legalservices/rgo/regprojs/whatdocs.html

Appendix G

Local NHS Ethical Approval

NHS
National Research Ethics Service

ISLE OF WIGHT, PORTSMOUTH & SOUTH EAST HAMPSHIRE
RESEARCH ETHICS COMMITTEE
1ST Floor, Regents Park Surgery
Park Street, Shirley
Southampton
Hampshire
SO16 4RJ

Tel: 023 8036 2863
Fax: 023 8036 4110

Email: scsha.SEHREC@nhs.net

MFK

9 July 2009

Miss Emma Hines
Trainee Clinical Psychologist
34 Bassett Crescent East
Universityof Southampton
Southampton
SO17 1BJ

Dear Miss Hines

Study Title: **A Qualitative Study of the Experiences of Younger People with Dementia**
REC reference number: **09/H0501/38**
Protocol number:

Thank you for your letter of 12 June 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

Appendix H

IPA Workshop Certificate of Attendance

Aston University
Life & Health Sciences

This is to certify that

Emma Hines

has attended a 1 day

Interpretative Phenomenological Analysis

Professional Development Course

17th July 2009

Dr Julia Brown
Director of Business & Marketing

Appendix I

Reflections on the Researchers Perspective

Qualitative methodologies take into account the importance of reflection on the researchers perspective and the social context of the relationship between the researcher and the participants (Yardely, 2000). Therefore the researcher feels that it is important to give an account of the researchers reflections on undertaking this piece of research, motivations for this project and relationship developed with the participants.

Firstly I will discuss my motivations for undertaking this piece of research. Prior to beginning training on the clinical psychology doctorate course I worked as an assistant psychologist in an older people mental health team. As part of this role I worked on a community psychology project with younger people with dementia and my interest in working with people with dementia first began. During this time I was interested in ways in which experiencing dementia may be different for a younger person compared to older people. I was shocked and frustrated to find that younger people were often placed in elderly care homes in the locality of our team and felt that the individuals placed there often experienced inappropriate care, support and activities for their age. I was keen to conduct my project with younger people with dementia and when I began looking for research in this field I was surprised to find that there was very little research involving younger people. This is what led to my beginning this project as an exploratory study keen to gain an insight into younger people experience.

I am aware that being a relatively young person and a trainee clinical psychologist will have had an impact on the relationship formed with the people with dementia I interviewed. It is possible that the participants wanted to present a positive image of living with dementia as the study may have felt threatening to them by exploring issues of their experience and sensitive issues of coping. The reflections noted by Steeman et al. 2007 suggested that asking questions in an un-empathic way led to participants presenting an extremely positive story of dementia which changed when the interviewer altered their approach to questioning. Following reading these reflections I felt it was important to build a relaxed, non-threatening relationship with the person I was interviewing. Using clinical skills and building rapport helped the interviewee to feel relaxed. I adopted a curious approach with participants encouraging them to tell me their story whilst attempting to refrain from indicating any pre-conceptions or expectations of what they might say.

Appendix J

Excerpt of Analysis

GN, 58, Female, Diagnosis – Alzheimer's

In: so you were saying that driving has been a big issue?

GN: put it this way I had to walk everywhere.

lking negative

In: right

GN: yeah although actually I do need to loose you know some of that (pats stomach)

Loss of driving

In: so it's good for you?

GN: well, yes but urm you know sometimes I miss I want to go somewhere quickly and sometimes it's too far away. I'm fortunate actually that I've got a friend of mine…I have known her for a long time and urm if I wanted to do something she would help because she's retired. Although she sometimes goes back to what she does and then…uh forgotten what I was going to say!

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iend helpful supportive

Miss driving

Support from friend

? Loss of independe

In: OK, so you've got some support around you then if you need it.

GN: yeah.

In: how did this all start for you then?

GN: urm, I was teaching, mostly science, I was the head of science at the time, but urm, I just couldn't urm, it was difficult to remember things, urm, I didn't really understand what was going on, at the time, urm my husbands urm, he ur, he works at the university and he also urm he work urm to get some more money he, cos of course 4 children are quite a lot to… *laughs*

s teaching

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Confusion

In: yeah.

Financial implications

GN: yeah that was urm, I, I've been, I find it difficult because, at the moment as well, urm money comes into it because I've lost what was a lucrative urm, yeah and urm, I couldn't believe it when they told me that I had…I couldn't I mean I'm 58 and I just, I don't, I mean its for people older than that! So it was and what was, I knew urm, my mother had died just about that time as well which didn't help. So….

fficult

ances

dn't believe

it 58

ds

pr people older

Loss of income

Incongruent with age

Shock at diagnos

In: right, yeah, how long ago was that then?

GN: that was beginning of…going back about 18months, yeah.

In: right, so that must have been a really difficult time.

GN: yes, yes it was, she was very ill, but it's just a shock anyway, it always is when you have a death. Yeah.

In: and so you noticed for yourself that there was problems with your memory and you said that it was affecting you work?

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Support from husband

GN: well its just, my husband, he was very nice actually, he well said cut the crap and go and do the right thing but what he was doing he by then it was obvious that I wasn't able to teach, so urm, he wanted, what was the problem and urm, we went through everything and then it just popped up. And I, I couldn't believe it, I didn't even know what the name was you know, so at the beginning I was, I was upset obviously and I just carried on as much as I can but I, and then again he gave me, it was obvious, obviously things were happening that I couldn't actually remember about, I'd be making something to eat and I, for the children and I couldn't remember what I was supposed to be doing, things like that and I but I, now that I know its obviously it makes me feel better because urm well, I know what I can and cannot do, urm I, I'm actually, over time, actually when I found out that I wasn't going to be allowed back to school definitely and I wasn't going to, I had to give it up I basically, I can't really get another job or anything like that, basically, which I mean I was always, I've had 3 careers in my lifetime and I just, I was, I've been teaching for ten years, and I'd actually worked for a, at the [redacted] in [redacted] and I'd also spent time in my first…my first career, I really, I had been making up and urm, making, what we were doing, we were making antibiotics and I had to get the bug to get it to go into…

Shock & disbelief at diagnosis

Loss of skills

'carried on'

Diagnosis positive – knowing & can

n & cannot
not allowed
school
ive up

or 'not allowed back at school'

Loss of job

In: so you're a real scientist then?

nted to teach

GN: yeah, really, and urm, but I had this thing, I wanted to teach because I found that when I was at the university, I was only there, urm, 3 years and that's where I met my husband, so I've got two plus two!

In: oh right OK

GN: I was married before, so I've got girl & boy, girl & boy!

In: right, so they are equal numbers!

GN: yes, mind you James was urm, we didn't know about him coming and my husband said, ' we can't, we can't' but well urm luckily, it's not a particularly big house but we have four bedrooms so we bunged my eldest in the smallest room! And we put the cot in our, and we had the other two in the other, and it was, yeah! Not babies, but there was people everywhere! *laughs*

In: how old are your children? *laughs*

n it
member

GN: my daughter in fact, she's got married, she's the eldest, and she's four weeks ago she got married. She went to urm, oh, I don't know which particular, I can't remember the name of which, of the university but she was down in devon but she was urm, but she met someone there and fell in love and they got married. And then there's [redacted] he's now, he's 26 and he's a teacher,

Appendix K

Principles of Quality Qualitative Analysis as outlined by Yardley (2000)

Yardley (2000) attempts to define principles which can be used flexibly as a guideline to assess the quality of a qualitative project. These include;

1. Sensitivity to context i.e. developing a sophisticated relationship between research findings and the existing literature. This highlights the importance of the context of theory, taking into account previous research in the chosen topic area, or research employing similar methodology. Also important when considering sensitivity to context is the social and cultural environment in which the research is conducted.
2. Commitment and rigour i.e. prolonged engagement with the topic and developing competence and skill within the methods used. Rigour refers to the resulting completeness of the data, this is related to the adequacy of the sample in terms of its ability to supply all information needed for a comprehensive analysis.
3. Transparency and coherence. This refers to presenting the analysis process in a clear manner and detailing every aspect of data collection and analysis. It is also important to highlight excerpts of transcript to the reader for they themselves to discern the analysis process.
4. Impact and importance i.e. as with any piece of research it can be judged on its impact and utility in the clinical field. This is important when discussing any type of research and research's usefulness can often be defined by it's value to those to which it was intended.

Appendix L

Guideline for Authors to Dementia Journal

You are in North America
Change location

SEARCH Journals

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About the Title
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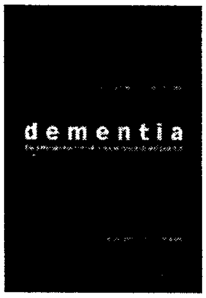
Plant & Agricultural Sciences
Politics & International Relations
Psychology
Public Health
Research Methods & Evaluation
Social Work & Social Policy
Sociology
Theology and Biblical Studies
Vocational & Professional Studies



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Dementia

The International Journal of Social Research and Practice

Editors: John Keady University of Manchester, UK
Phyllis Braudy Harris John Carroll University, Cleveland, USA

Manuscript Submission Guidelines:

Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.

2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.

3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.

4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.

5. Your typescript (written in English) needs to be typed using double spacing on one side only of white Aor US standard size paper, with generous left and right-hand margins (at least .cms) but without justification.

6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.

7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.

8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.

9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.

10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

11. *Figures.* Line drawings should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

12. *References in the text* should be presented in American Psychological Association (APA) style, i.e. the author's name and year of publication in brackets, together with the page numbers, e.g. 'As Kitwood (1997, pp 40-41.) has observed', or, in a more general reference: 'Kitwood (1997) appears to be saying ...'

13. *Reference list.* The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17(4), 597-607.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

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