PhD Document

Title of project: The role of the Community Nurse in bereavement support

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Abstract

Evidence from studies conducted in North America and Australia suggest that bereavement increases the risk of mental and physical health problems although in the United Kingdom the extent of this problem remains largely unknown. In the community the District Nurse Service plays a pivotal role in the provision of palliative care, however, little is known about nurses' views on bereavement support or their actual involvement.

This thesis presents three studies that report bereavement from the primary care perspective in the United Kingdom. The first study describes a prospective exploratory case study which was conducted with 13 bereaved people, who were recruited through primary care practitioners and funeral directors, to measure the impact of bereavement on aspects of mental health.

The second study reports a postal survey which aimed to ascertain the current practice and perceived role in supporting bereaved people from a representative sample of district nurses in the central southern coastal area of Britain. This achieved an overall response rate of 62% (323) following two reminders.

The results of the postal survey led to the third study which reports a series of in-depth audio-taped interviews with 22 district nurses. Using a qualitative methodology this explored in greater depth the perceived role, beliefs, value and motives of district nurses in bereavement support.

The results suggest that greater clarification of the future role of the District Nurse Service in bereavement support is warranted. District nurses require better training and awareness of bereavement issues at pre and post registration and to improve their awareness of available bereavement support at both a local and national level. District nurses would be suited to a role in the assessment and referral of bereaved people to other services, although a specialist bereavement role does not appear to be welcomed by most district nurses.

In the final chapter I critically explore and reflect on the difficulties experienced while attempting to perform research with bereaved people and provide evidence to suggest that my research has been affected by a fundamental shift in society's view of bereaved people which may explain many of the difficulties experienced.

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CONTENTS

Chapter 1 Introduction

Chapter 2 Literature review of bereavement

Chapter 3 Methodology

Chapter 4 Interviews with and assessments of bereaved people

Chapter 5 A postal Survey of District Nurses

Chapter 6 Interviews with district nurses

Chapter 7 General Discussion

Chapter 8: Conclusions and theoretical discussions

Tables

Figures

Graphs

Diagrams

Boxes

Chapter 1 Introduction

1.1 Bereavement and grief.

Death is an inevitable consequence of life; however, knowledge of this fact does not lessen the impact that the death of a loved one can have. Those bereaved may experience great emotional distress and social upheaval. Bereavement also increases the risk of mental health problems particularly depression and the risk of physical morbidity and mortality.

The terms 'bereavement' and grief have a common etymology from the Old English word 'reafian', to plunder, spoil or rob. Taken in this wider context the term 'loss' is often used and individuals may experience 'loss' or 'bereavement' following the loss of their job, their liberty, a pet, health or a limb following amputation. The terms grief, bereavement and mourning are often used interchangeably although their meanings are quite distinct. Bereavement can be defined as a loss which can include loss through death; grief is the emotional response to that loss, and mourning the manner in which grief is expressed within the socio-cultural and religious context of the bereaved person (Stroebe, et al 1999). In this thesis bereavement refers specifically to the death of a close person.

1.2 Bereavement support in the community

British society has undergone much change since the Second World War. It has developed into a multicultural society but has also become increasingly secularised (Walters, 1999). In general there has been a break down of the extended family and increased mobility of nuclear families. Whereas previous generations had roots within a community, the post-modern family may be extended across the world. The impact of these changes can be seen with bereaved people who may not have the emotional support network, previously provided by the family, clergy and local community. Increasingly people are turning to health professional and the state for support at times of need. There is evidence that some bereaved people increase their use of health care resources, particularly their general practitioner (GP) following the death of a close relative.

However, the role of the primary care team in bereavement support remains unclear and one must question whether 'uncomplicated' bereavement should be viewed as a 'medical' problem. One can argue if bereavement is natural and grief a normal reaction to bereavement why carry out bereavement support in primary care?

For most members of British society the expression of grief following the death of a close person is generally perceived as an expected and 'normal' reaction to the loss. Most people cope with bereavement without any intervention; however, some may experience a deleterious impact on physical or mental health, particularly those who are vulnerable or elderly. In addition a small minority of bereaved people may experience unresolved or complicated grief and require professional help and support. The majority of people with depressive and anxiety disorders are treated by GPs and the primary care team and not the secondary health services (e.g. psychiatry). It is therefore important that the primary care team are able to identify, assess and treat bereavement related problems.

1.3 The Primary Health Care Team.

Although the composition of the PHCT will vary depending on particular general practice, the Royal College of general Practitioners has identified a core PHCT as consisting of the following members: a GP, practice nurses, community nurses, health visitors, practice managers and administrative staff (RCGP, 1998). In addition there may also be other members such as midwifes, physiotherapists, counsellors, clinical psychologists, occupational therapists, psychiatric nurses, and dieticians.

In his book 'The Primary Health Care Team' Hasler (1994), describes the slow development of the PHCT following the introduction of the NHS in 1948. One survey found that 41% of GPs had never or hardly ever met the district nurse who looked after most of their patients (Hockey, 1966).

Today Community Nurses include: district nurses (DNs), health visitors, practice nurses, school nurses, community psychiatric nurses, occupational health nurses, and specialist nurses, such as diabetic and stoma care nurses. A DN is defined as a nurse who works in the community and has a DN qualification recorded on the nursing registrar of the Nursing and Midwifery Council (NMC), however it is a mandatory qualification that should only be applied to those that hold it. District nursing is a branch of the nursing profession that offers comprehensive nursing services to people living in the community. DNs work mainly with GPs, but also other health professionals such as occupational therapists, chiropodists, physiotherapists and speech therapists, social workers and also some voluntary organisations. They work in a variety of settings including people's own homes, health centres, GP surgeries, schools and the workplace. However, for this thesis DNs will be defined in a broader sense to include community staff nurses working alongside DNs who do not have the DN registration.

The PHCT makes an important contribution to the overall well being of people in the community and eight key functions of the PHCT have been defined by the RCGP as:

1. *The diagnosis and management of acute and chronic conditions, treatment in emergencies, when necessary in the patient's home*
2. *Antenatal and postnatal care, and access to contraceptive advice and provision*
3. *Prevention of disease and disability*
4. *The follow-up and continuing care of chronic and recurring disease*
5. *Rehabilitation after illness*
6. *Care during terminal illness*
7. *The co-ordination of services for those at risk, including children, the mentally ill, the bereaved, the elderly, the handicapped and those who care for them*
8. *Helping patients and their relatives to make appropriate use of other agencies for care and support including hospital-based specialists*

(RCGP, Information sheet 21, The Primary Health Care Team, 1998: page 2)

The seventh function makes explicit reference to the coordination of services for those at risk including bereaved people and those with mental health problems. However, little is known about the sort of support that is provided by the PHCT to bereaved people or the impact of that support on their well being. Most members of the PHCT have contact with bereaved people, and the GP and the DN service are pivotal to palliative care in the community (National Institute of Clinical Excellence NICE, 2003). Many patients receiving palliative care leave bereaved relatives, and in addition the GP, health visitor and community midwife may provide support to parents who have suffered a miscarriage, or the death of their baby or child.

1.4 Background to the thesis

A typical practice with four GPs and a patient list of 8000 will have around 80 patient deaths per year. GPs and DNs frequently care for patients with terminal illness in the community and one survey of DNs reported that 69% had cared for between one and ten patients dying from cancer or AIDS in the past year (Hatcliffe et al, 1996). However, there is little apparent agreement between health professionals about the best way to deal with bereaved people.

The evidence of increased health risks following bereavement has led some GPs to advocate a proactive bereavement protocol for the PHCT (Charlton and Dolman, 1995). However, others have questioned the advisability of adopting such protocols unreservedly, without evidence that active follow-up in primary care improves outcomes (Woof and Carter, 1995). In general GPs are unsure about how to treat their bereaved patients. A recent survey of GPs to ascertain bereavement support and practice activity following patient deaths found responders were equally divided over whether bereavement support should be proactive or reactive. One of the reasons for not following up bereaved relatives proactively was a concern not to 'over-medicalise' grief (Harris and Kendrick, 1998). Anecdotal evidence suggests that an important role of the GP and DNs is often simply to be there and listen to the bereaved person and to recognise grief as a painful but normal process. Similarly making contact with the bereaved person can be appreciated and remembered.

There is some evidence of increased utilisation of primary and secondary health services in the UK and Canada after bereavement (Parkes 1964a, Tudiver et al 1995) but not all studies have found this to be the case particularly in North America (Parkes and Brown 1972). Parkes has argued that the financial cost of medical care at the point of delivery in the United States (but not Britain), may act as a deterrent to those seeking help and result in an underestimation of the true impact of bereavement on health (Parkes, 1998).

The views of DNs about their provision of bereavement support has not been investigated and remains unknown. There are few published guidelines or policies to advise DNs on their role in the provision of bereavement support. However, Koodiaroff (1999) writing from an Australian perspective suggests that when 'community nurses' have provided palliative (terminal) care in the community they are ideally placed to offer bereavement support. Others agree and suggest that DNs could potentially play a key role in assessing the needs of the bereaved person, helping them with the pain of grief, offering advice, support and information (Costello, 1995; Monroe and Smith, 1997) and helping to prevent any breakdown in health.

Although it appears reasonable to expect DNs to be able to offer support and information to families immediately following the death of a patient they have cared for the provision of long-term bereavement support may be perceived by some DNs as an attempt to extend and perhaps expand their role beyond its current remit. How DNs perceive their role in bereavement support remains unclear and is an area that needs further exploration. Similarly what DNs actually do in their provision of bereavement support needs to be explored and the benefits to bereaved people assessed. The provision of bereavement support raises a number of unanswered questions about the ability of the DN service to provide such support. The DN service is time pressured with limited resources and some DNs may lack skills and appropriate training in dealing with bereaved people. These are issues that should be addressed and the views of the DNs sought before changes are implemented at a local or national policy level.

1.5 Development and focus of the thesis

It is evident from the literature that bereavement support is an area that has received little attention in primary care. Anecdotal evidence suggests that GPs and nurses receive little training in how to deal with bereaved people, which may reflect a lack of priority in health care or a reluctance to deal with such a sensitivity and emotive subject.

In recent years there has been widespread publicity following the aftermath of traumatic deaths such as the Hillsborough football tragedy on 15th April 1989 when 96 football fans died, which has identified the need for bereavement support for grieving people. These issues relating to deaths and bereavement have firmly put bereavement support into the public arena and onto the health agenda. However, the focus of bereavement support has mainly been on specific tragedies and within hospital settings with little guidance about bereavement from the primary care perspective. For example the Alder-Hey inquiry into the retention of human tissue at the Royal Liverpool Children's Hospital significantly raised the profile of the need to support bereaved families (HMSO, 2001). One of the key issues raised in the Alder-Hey enquiry was the need for the provision of information and support to bereaved parents, which the report suggested should be carried out by a bereavement advisor (HMSO, 2001). Any such adviser would be based within the hospital trust. In an earlier interim report on guidelines for post mortem examinations the chief medical officer had recommended that all NHS hospitals Trusts should designate a named individual in the trust who should be available to provide support and information to families of the deceased where a post-mortem was required (Department of Health, 2001a). It was also suggested that this person was trained in bereavement support. Again the focus of attention was within the hospital and not the wider community.

To redress this current imbalance this doctoral work aimed to focus specifically upon bereavement support from a primary care perspective. As a researcher I felt suitably qualified to explore the issues of bereavement support from a primary care perspective. I had a unique background as a general nurse, with a masters degree in psychology and experience of and interest in mental health research into depression and anxiety. This blend of experience and interest enabled me to consolidate my knowledge of mental health, nursing and psychology to explore bereavement issues in primary care.

The programme of doctoral research has been substantially modified and developed from its initial conception. This has come about through a process of critical reflection on both the research process and the preliminary research findings from the first study. The initial aim, based on the preliminary review of the literature, was to evaluate the impact of bereavement on the mental health of bereaved people sampled from the primary care population of the UK

There was evidence from studies conducted in the USA and Australia, that bereavement increased the risk of mental and physical health problems in bereaved people, but, the extent of the problem in the UK remained unclear. An extensive literature search identified some relevant published literature on the prevalence of psychiatric morbidity following spousal bereavement in a UK primary care population, but these had specific deficits in their methods. In brief it was clear that little was known of the full range of mental health problems in bereaved people outside selected groups in specialised settings.

I therefore decided to evaluate the impact of bereavement on mental health problems experienced by bereaved people from a representative sample of the primary care population. This was primarily designed to address the hypothesis that in a UK primary care population spousal-bereaved people had significantly more levels of depression and anxiety than non-bereaved married people. It was possible that some patients might be reluctant to seek help due to the fear of the stigma of being diagnosed as having a mental health problem, and therefore many problems may go unreported and undetected. It was hoped that following an evaluation of the extent of mental and physical health problems in a sample of bereaved people in the community it would be feasible to develop a randomised controlled trial of a specific primary care intervention for bereaved people to assess and respond to the impact on mental and physical health. To address the initial research question I designed an exploratory study to evaluate the physical and mental health problems of bereaved people in the community and the primary care support provided to them. This was the first study and is reported in Chapter 4. A prospective case-control study design was chosen to describe the mental and physical health problems of spousal-or partner-bereaved people from a general practice population which were to be age-matched to a non-bereaved control group. The primary outcome measure was chosen as the clinical interview schedule-revised (CIS-R) (Lewis et al, 1992) and based on my power calculations it was calculated that 65 bereaved and 65 non-bereaved (married-control) people were required to give 80% power at the 5% level of significance.

Due to the sensitive nature of the research a number of ethical issues were encountered giving rise to some delays in approval by the Local Research Ethics Committees (LRECs). These are described in Chapter 4. During the study the recruitment of bereaved people within the limited time frame became a significant and eventually insurmountable problem. Overall only 13 bereaved people participated and the study was eventually limited to a case-series, which could nevertheless provide some information and serve to warn other researchers about the difficulties involved in recruiting bereaved people through the methods attempted.

Through my reflection on the research process and discussions with the bereaved people I interviewed I decided to critically review the method and focus of this doctoral research. A key shift in my thinking came about through my evaluation of the bereavement literature based in the community in particular the nursing literature. From that I located much that reported the DN service as an essential component to palliative care in the community but identified very little literature about the role of the DN in bereavement support. Their role remained undefined and under researched although I knew from my own personal experience as a student nurse and from discussions with nursing colleagues that some DN carried out bereavement visits in the community.

A major influence on nursing practice has come from the drive to see nursing as a profession founded on a discrete knowledge base. This has demanded that nurses move away from 'ritualistic' care (Walsh and Ford, 1991) to become reflective practitioners who critically evaluate research evidence.

I carried out an extensive literature search of the key databases to identify key papers relevant to the DN role in bereavement support. The results suggested that within the UK little was known about the DNs involvement in bereavement care and there were few published guidelines or research on which they could base their clinical practice. This led me to develop a second study using a postal survey designed to collect a broad spectrum of information and experiences from a large cross section of DNs. The postal survey aimed to describe the current practice and perceived role about bereavement care in the community from the DN perspective. This research was subsequently published (Birtwistle et al, 2002) and is described in Chapter 5. Based on the results of this survey and my critical reflection of the data, published literature and discourse with DNs, I designed a third study to explore in greater depth the perceived role, beliefs, values, and motives of DNs in bereavement support. This used qualitative methodology and involved a series of audio-taped interviews with a broad range of DNs. This will be described in Chapter 6.

The evidence base on which practice is grounded can come from both quantitative and qualitative research and the nature of district nursing with its multidimensional aspects (medical, psychological, social) lends itself to both quantitative and qualitative research methods. As an under researched area this doctoral work has important practical implications for bereavement support in the community and for the training and continued education associated with the extended and expanded role of the DN in bereavement support. Chapter 7 provides a general discussion of the three studies and outlines recommendations for the role of the DN service in the provision of bereavement support in the community.

Finally, Chapter 8 provides a critical exploration and reflection on the difficulties experienced while attempting to perform research with bereaved people. This chapter integrates wider sociopolitical issues identified in the research with a theoretical discussion of bereavement support.

Chapter 2 Literature review of bereavement

This chapter will present a critical review of the literature relevant to this thesis. It is presented in two main sections. The first section provides a review of the literature relevant to the impact of bereavement on health. This section starts with an introduction to the main theories of grief, a brief review of mortality following bereavement, and a more detailed review of morbidity following bereavement with particular reference to mental health problems. The second section focuses on the literature relevant to the provision of bereavement support from the Primary Care Team, specifically the role of the GP and District Nurse.

2.1 Theories of Grief

The following will provide a brief overview of the main theories of bereavement. The word limit prohibits an extensive review.

2.1.1 The psychoanalytic school

The modern concept of grief can be traced to the writings of Sigmund Freud in particular his seminal work 'Mourning and melancholia' (Freud, 1917) which provided one of the first models for the understanding of grief following bereavement and remains an influential theory. One survey of bereavement experts revealed that 66% claimed the psychoanalytic theory to be one of the three most useful models (Middleton et al, 1991, cited in Hagman, 1995). Freud used mourning (grief) as a model for his psychoanalytic theory of the development of melancholia (clinical depression). Grief was argued to be a normal psychic process while melancholia was not. Freud suggested grief was the normal process by which the ego withdraws its attachment to the lost object/person so that it can reinvest its energy into other objects (e.g. people). The term decathexis was used to explain the process by which the ego invests the large amount of psychic energy required in order to withdraw its attachment to the lost object/person. This he argued explained the increased inhibition and loss of interest seen in those who were mourning, a process termed 'grief work'. Freud identified four characteristics of normal mourning: namely a profoundly painful dejection; a loss of capacity to adopt new love objects; a reduction in activity or a withdrawal of activity not connected with thoughts of the loved person; and a loss of interest in the outside world because it does not involve the dead person.

Freud's paper has been influential to many models of grief and particularly the work of Helen Deutsch (1937). Deutsch (1937), argued mourning was a pre-requisite intra-psychic process necessary for bereaved individuals to achieve mental health. The *absence* or suppression of grief was argued to be pathological which would find an expression in the form of psychopathology or psychosomatic illness. This concept has influenced much of the views about the normal aspects of grief and has led many to suggest that bereavement may be an aetiological factor in the development of a number of psychological and physical disorders e.g. ulcerative colitis, rheumatoid arthritis and asthma (Lindemann, 1945).

Another key paper in the development of the psychoanalytic model of grief came from the psychiatrist Lindemann (1944). In it he provided a valuable description of the features of normal 'acute' grief and pathological grief, which formed recognisable syndromes. Like Deutsch (1937) Lindmann argued that some patients with 'absent' or 'delayed' reactions were prone to unfavourable behavioural disturbances and others to psychosomatic disorders e.g. objective organic manifestations (e.g. ulcerative colitis). However, his observations were based on his psychiatric interview of 101 'psychoneurotic' patients with mixed aetiology. Some had lost a relative during the course of treatment, others were relatives of patients who had died in hospital, 13 were bereaved from a Boston night club fire disaster (Cocoanut Grove), and there were also relatives of members of the armed forces. Acute grief was defined as a syndrome with psychological and somatic symptomatology. Five components of this were somatic disturbance, preoccupation with the image of the dead; guilt; hostility; and disorganised behaviour. Normal grief was suggested to only last for several weeks and he claimed:

> '*With eight to ten interviews in which the psychiatrist shares the grief work, and with a period of from four to six weeks, it was ordinarily possible to settle*

> *an uncomplicated and undistorted grief reaction. This was the case in all but one of the 13 Cocoanut Grove fire victims'*. (Lindmann, 1944: p157).

Freud did not consider grief a psychopathology requiring treatment; rather he suggested that any therapeutic intervention might be harmful in normal grief (Freud, 1917). Klein however, believed that mourning was an illness and that the mourner went through a modified and transitory manic-depressive state. She states:

> *'The mourner is in fact ill, but because this state of mind is common and seems so natural to us, we do not call mourning an illness'*
> *(Kleine, 1940: p 321).*

Such conceptualisations have been influential in promoting the management of bereaved people within the medical model as patients requiring assessment, diagnosis, and treatment.

2.1.2 Phase or stage theories of grief

Alongside the psychoanalytic view of grief, the phase or stage theories (Bowlby, 1980; Parkes, 1971; Kubler-Ross, 1969; Worden, 1999) are probably the most familiar to those working in primary care. These models of grief propose that people bereaved through death or loss go through a number of stages or phases to a point of recovery. This has parallels with the medical model and links grief with the characteristics of a disease process (Engel, 1961).

Kubler-Ross (1969) Based on her clinical work as a psychiatrist with terminally ill people she suggested that there were five general stages, namely denial and isolation, anger, bargaining, depression, and finally acceptance. Subsequently this model has been applied to bereaved people.

Bowlby (1980) attempted to revise the psychoanalytic approach to grief by combining it with animal research, giving rise to his attachment theory. Based on his observation of animals and children separated from their mothers, he theorised that human grief was a form of separation anxiety with a biological foundation. He suggested there were four main phases of grief: numbness; yearning, searching and anger; disorganisation and despair; and reorganisation.

Parkes (1971) developed a similar four phase model independently from Bowlby and later developed research collaboration with him. Parkes (1971) suggests grieving was a psychosocial transition because loss and bereavement challenge the assumptive world of the bereaved person who must adapt to their loss. Parkes identified numbness, pining, depression and recovery as relevant stages in grief.

Worden (1982, 1999) drew upon the grief theories of Freud (1917), Bowlby (1980) and Engels (1960) and suggested grief was a process and not a state and that there were four tasks of mourning that needed to be accomplished for equilibrium to be achieved. In his view grieving serves a specific purpose and the 'work of grief' is necessary to enable the bereaved to move on in their life. It is assumed that successful adjustment to loss requires that individuals 'work through' or deal with their feelings rather than denying or repressing them. The four tasks proposed are: to accept the reality of the loss; to work through the pain of grief; to adjust to the environment without the deceased; and to emotionally relocate the deceased and move on with life.

In general the authors of the various stage or phase models do not propose that there was any specific linear order to how a bereaved person would move through the stages and it is suggested that people can miss out stages or even repeat them.

2.1.3 Dual process model of grief

Stroebe and Schut (1999) developed an alternative view of the process of grief termed the dual process model (DPM) of grief. Based on their empirical work they confronted many of the inherent criticisms of the models of grief that suggested that avoidance of grief was detrimental. The DPM proposes that bereaved people oscillate between two processes of adaptation to the loss; loss orientation and restoration orientation. Loss orientation appears synonymous with grief work with the bereaved person demonstrating a preoccupation with the loss, and behaviours and activities associated with sadness, rumination and yearning for the deceased person. However, restoration orientation, involves coping with everyday life, such as trying to rebuild a new identity and the skills required to adjust to life without the deceased person.

The authors argue that it is important that bereaved people take time off from grieving as the emotions would be overwhelming. Based on their empirical research the authors propose that there will be variability in the amount of time spent between loss and restoration orientation. This will depend upon circumstances of the loss, personality differences, gender and culture. The DPM places much emphasis on the psychology of grieving which may be to the detriment of the social context of the loss. However, it does enable different coping styles to be seen within a normal context of grieving.

2.1.4 Continuing bonds with the deceased

Two recent models have criticised the predominant concept of grief as being a working through of emotions to an eventual goal of moving on. Walter's Biographical model of grief (new model of grief) supports the importance of maintaining a relationship with the deceased (Walter, 1996). Through the process of talking with others who knew the deceased person, bereaved people construct a biography of the deceased which they incorporate into their daily life. The biographical model promotes the social and interpersonal context of bereavement, with little emphasis on the emotional aspects of grief. Walters suggests that some people need to go through this biographical process to work out what the deceased person meant to them. While some aspects of Walters's model have an intuitive appeal, there have been no empirical studies using the model. In addition much of the theory was based on his own personal experience of loss. However, it does provide an important and supplementary perspective to the knowledge of bereavement and loss.

Klass et al (1996) have criticised the predominant belief that the purpose of grief is to sever bonds with the deceased. They suggest that models based on disengagement (from the deceased) exclude experiences and evidence which are inconsistent with those views. They suggest that much bereavement research has used quantitative research (positivism) which has excluded the voice of the bereaved. Klass et al (1996) therefore promote the use of qualitative research methods in an attempt to understand the meaning of bereavement within the social context of those bereaved.

2.2 Mortality after bereavement

The following will briefly summarise the key research findings of the impact of bereavement on mortality. The focus of this thesis is bereavement support from the primary care perspective and not the epidemiology of bereavement mortality. This has been instrumental in the approach I have taken to searching for and reviewing the literature. As part of my background reading I explored the literature assessing the impact of bereavement on mortality because this raises important issues about health following bereavement. The literature on the mortality of bereavement was obtained in three ways: reading two key texts (Stroebe et al, 1999; Stroebe & Stroebe, 1994) and a literature search of the main electronic medical databases, and scanning the reference section of articles obtained from the search. For the search I used three key electronic medical databases: Embase (1980-August 2001), Medline (1966-September 2001), and Cinahl (1982-July 2001) with the key search terms: [(bereave*) or (grief) or (widow*)] AND [mortality]. However, this topic will not be reviewed in detail in this section; rather I have provided a summary of the main articles and findings in Table 2.1 below. The majority of bereavement mortality research has focused on spousal bereavement. However, there is a substantial amount of literature on mortality following the death of a child, or a partner due to HIV / AIDS. However, the deaths due to HIV / AIDS were too specific for inclusion in this review, also the death of a child is a comparatively rare event in British primary care compared to the death of a spouse or partner. For this brief overview I have focused on spousal bereavement, which typically reflects the majority of bereavement in the primary care setting.

Table 2.1 provides evidence that spousal bereavement increases the risk of mortality particularly in men within the first six months of widowhood. The excess mortality appears to be greatest in the younger age groups (particularly men), but may also be evident in old widows. There is some evidence of an increase in death from cardiovascular disease, suicide and alcohol-related diseases. Suicide and alcohol related deaths may reflect underlying mental health problems, which are areas that need to be addressed. This has important implications for the primary care team in their identification and support of bereaved people who may be at risk. Evidence for an increased risk of mortality following bereavement has come from several large scale studies assessing the impact of marital status on mortality (Kraus and Lillienfeld, 1959; Mergenhagen et al, 1985; Hu and Goldman, 1990; Ben-Shlomo et al, 1993).

Mergenhagen et al (1985) carried out a large scale cross sectional survey based on mortality data from the US National Centre for Health Statistics (NCHS). He calculated "marital status mortality ratios" (MSMRs) for the years 1959-61 and 1979, for the marital status groups 'never married', 'widowed' and 'divorced' by dividing the mortality rate per group by the rate of the corresponding married group. A MSMR of 3 would indicate three times the rate of death, compared to married people of the same gender and age category. Age categories were 25-44, 45-64, and 65 years or older. In the survey of 1979 younger widows aged 25-44 years had the highest MSMRs compared to the other aged widows. In addition men were higher than women in most categories. Those categories with increased MSMRs (men / women) were: suicide (12.28 / 3.61 respectively), homicide (men only 5.10), motor vehicle accidents (5.34 / 6.46), other accidents (4.87 / 5.97), diabetes (8.68 / 2.77), cirrhosis of the liver (9.02 / 4.25), lung cancer (6.27 / 2.21), cancer of the digestive system (women only 3.31), arteriosclerotic heart disease (3.82 / 3.54) and cerebrovascular disease (women only 2.41).

Hu and Goldman (1990) carried out an international comparison of the mortality differentials by gender, age, marital status (single, married, widowed and divorced) for 16 developed countries including England and Wales (years 1965, 1971, 1979, and 1984). When all countries were combined the estimated "relative mortality ratios" (RMR), relative to married persons, were higher for both men and women in all the unmarried groups (single, widowed and divorced), and larger for men (average RMR = 2) than for women (average RMR = 1.5). The relative mortality ratio is defined as the relative risk of death in each group (e.g. age, gender, and single marital status) compared to a married sample from the same comparison group. In the above example unmarried men were twice as likely to die as married men. In most countries divorced men have the highest mortality rate. However, age-specific effects were also reported and the highest mortality was seen with young widows in their twenties and early thirties who often had a RMR of 5 with some reported to be as high as 15. There was a similar pattern seen across several countries. Ben-Shlomo et al (1993) reported similar findings in an analysis of the data from the UK Whitehall study, an 18-year follow-up of 18,403 men aged 40-64 years working in the Whitehall civil service, London between 1967 and 1969. All unmarried men had a significantly higher total mortality than married men. The authors also found that widowed men had a significantly greater risk of dying from cardiovascular disease (relative risk 1.34, 95% CI 1.03, 1.74) and specifically coronary heart disease (RR 1.46, 95% confidence interval 1.08, 1.96).

However not all studies have found widowhood to be associated with greater mortality (Ebrahim et al, 1995; Johnson et al, 2000; Cheung, 2000). As part of the British Regional Heart Study, Ebrahim et al (1995) used a prospective longitudinal cohort design to look at the health of British men in various marital status groups. They controlled for behavioural, health and socioeconomic factors measured at baseline. They followed 7,735 men for up to 11.5 years to assess the impact of marital status on mortality in middle aged British men. When adjusted for a number of potential confounders including age, social class, smoking, diabetes, blood pressure, cholesterol, alcohol, physical activity, employment status, widowed men were only at increased risk of other non-cardiovascular disease (RR 2.4, 95% CI 1.1-5.3). After adjusting for age there was no evidence of excess cardiovascular disease mortality among widows at baseline or those who became widows during the study (Ebrahim et al, 1995).

Cheung (2000) looked at a representative sample of British women as part of the Health and Lifestyles Survey (HALS) which carried out a baseline survey in 1984/85 and followed up in 1991/92. This comprised 9003 adults in England, Wales and Scotland. The sample looked at 3378 women who were aged 35 years or older in 1984/5 and followed them up until 1997, a total of 12.3 years. After adjusting for age and marital selection found that the hazard ratio for being single was associated with a higher mortality (HR 1.45, 95% CI 1.09-1.94), but being divorced or widowed was not (HR 1.09, 95% CI 0.73-1.61) and (HR 1.09, 95% CI 0.90-1.31) respectively.

In summary, although findings are mixed, there is evidence that being married exerts some protective effect on the health of men but less so for women. Unmarried men particularly those divorced or widowed have an increased health risk. Several studies identify a greater risk of mortality in younger widowed men. Socioeconomic factors and lifestyle have an impact on health status, which can combine with marital status. Although not all studies are directly comparable to the UK population, there is evidence that being widowed (particularly for men) coupled with socioeconomic deprivation increases the risk of poor health and mortality. These are factors that should be considered in primary care health policies.

Table 2.1: Key studies of mortality following bereavement in chronological order

Name	**Year**	**Country**	**Total number of subjects**	**Gender**	**Excess mortality (gender effect)**	**Duration effect**	**Follow-up**
Kraus & Lilienfeld	1959	USA	All deaths in USA 1949-51	M & F	Yes	Not assessed	N/A
Young et al *(see Parkes 1963)	1963	UK	4,486	M only	Yes	See Parkes 1969*	4 years
Ekbolm	1963	Sweden	643	M & F	Evidence[$] (Widowers)[$]	Non significant Tendency for first 6 months (ns)	3 years
Cox & Ford	1964	UK	60,000	F only	Yes	Second year	5 Years
Rees & Lutkins	1967	UK	903	M & F	Yes (Male relatives)	First year	6 Years
Parkes *(follow-up of Young et al 1963)	1969	UK	4,486	M only	Yes (Widowers)	More widowers in first 6 months	9 Years
McNeill	1973	USA	9,247	M & F	Yes	Widowers: < 60yrs in first 6 month Widows< 60 yrs, year 2.	3.5 years
Clayton	1974	US	109	M & F	No	None	4 Years
Ward	1976	UK	366	M & F	No (Widowers)[$]	More widowers in 6 months (ns)[$]	2 Years
Niemi	1979	Finland	939	M & F	Evidence[$] (Widowers)[$]	6 months (ns)[$]	12 years
Helsing et al	1982	US	4,032	M & F	Yes (Widowers)	No evidence	12 Years
Mellstrom et al	1982	Sweden	360,00	M & F	Yes	First 12 months for widowers First 3 months for widows	11 Years
Bowling & Benjamin	1985	UK	503	M & F	Yes (Widowers)	6 months (75+ Widowers only)	6 Years

[$] non-significant

Table 2.1 Continued: Key studies of mortality following bereavement in chronological order

Name	**Year**	**Country**	**Total number of subjects**	**Gender**	**Excess mortality (Gender effect)**	**Duration effect**	**Follow-up**
Kaprio et al	1987	Finland	95,647	M & F	Yes (Widowers)	First 4 weeks and 6 months	4 years
Jones	1987	UK	156,060	M & F	Yes (Widowers)	Widows peak in first 30 days. Increase lasts aprox 6 months. Widowers: raised over 1 year.	10 Years (1971 census data compared to 1981 census data)
Jagger & Sutton	1991	England	344	M & F	Yes (Widows)	Greatest risk of mortality in first 6 months.	7 years
Ben Shlomo Y	1993	UK	18,403	M only	Yes	Increased risk of death observed at 18 year follow up.	18 years
Mendes de Leon	1993	US	1,046	M & F	Yes	First 6 months	6 Years
Schaefer	1995	US	12,522	M & F	Yes	7 to 12 months following bereavement	14-23 Years
Ebrahim	1995	UK	7735	M only	Yes	Not assessed	11.5 years
Martikainen and Valkonen	1996	Finland	1,580,000	M & F	Yes (Widowers)	First 6 months	5 Years
Lichtenstein et al	1998	Sweden	35860	M & F	Yes	First 6 months	4 years
Johnson et al	2000	USA	281,460	M & F	Yes	Highest in first year	10 Years
Cheung	2000	Eng, Wales, Scot	3378	F only	No	No evidence	12.3
Nagata et al	2003	Japan	3505	M & F	No	No evidence	10 years
Manor and Eisenbach	2003	Israel	90,830	M & F	Yes (Widowers)	Greatest in first 6 months	9 years

$ non-significant

2.3 Increased morbidity after bereavement

Morbidity following bereavement covers a broad area and can prove difficult to search specifically. I started by reading three key texts (Stroebe & Stroebe, 1994; Parkes, 1998, Stroebe et al, 1999) to gain an overview of the literature and to identify key articles. Then I carried out a number of targeted searches using four electronic databases (Embase, Medline, PsychLIT, and Cinahl). Additional sources included the reference section of books and articles obtained from the search.

The initial search of the electronic medical databases was performed in June 1999 and covered Embase (1980-June 1999) and Medline (1966-June 1999) and the search terms bereave* or grief and was used to identify any literature in those databases that used those words in the title, abstract or key terms. This identified 8581 references, which were saved into the bibliographic management software Reference Manager (Reference Manager version 9, 1999). Over a period of two weeks the title and abstract (if available) of each reference was assessed and those that were of interest selected and the key articles obtained. Subsequent searches were performed with the final literature search being performed on 14th May 2003. Most were duplicates of the original search, although Cinahl provided some additional literature from the nursing perspective. The term widow* was excluded from the global searches as terms such as widow, widower, widows, and widowed are used in a large number of studies which use marital status as a classification and are often not specifically related to bereavement research. For example using the search terms bereave* or grief or widow* for a combined search of the databases Embase (1980 – August 2001), Medline (1966 – August 2001) and Cinahl (1982-July 2001) identified 16,176 hits, most of which were not appropriate for this review. In addition erroneous articles such as those regarding black widow spiders (namely venom) were also identified when the term widow was used.

Following my initial reading of the literature I decided to perform targeted searches specific to mental health problems of depression and anxiety. These used the general terms for bereavement or grief described above which were combined with specific search terms of interest. In addition attempts were made to refine the searches to only include those relevant to primary care by combining the hits with the following terms: 'primary care' OR 'general practice' or 'general practitioner' or 'GP'. However this was often too limiting, although it did enable the identification of key articles. All references were saved into Reference Manager and the articles obtained if suitable (see Table 2.2).

Table 2.2.

Target searches for mental health problems associated with bereavement performed on 14th May 2003 using Ovid technologies and the databases Embase (1980 – May 2003), Medline (1966 – May 2003), PsychLIT (1879-May 2003) and Cinahl (1982-May 2003) combined with the terms 'bereavement' or 'bereaved' or 'grief' and specific mental health key words anywhere in the text

Area of search	**Search terms used**	**Hits (with duplicates removed) when combined with bereavement' OR 'bereaved' OR 'grief'**	**Hits when combined with 'primary care' OR 'general practice' or 'general practitioner' or 'GP'**
Depression	Depression or depressive	2607	74
Anxiety	Anxiety	1294	31
Changes in alcohol use	Alcohol	180	14
Abuse of prescribed medication	Benzodiazepine **OR** sedative **OR** tranquilizer	30	4
Suicide	Suicide	1002	25
Bipolar disorders	Bipolar disorder or manic	138	6

2.3.1 Preliminary evidence for the impact of bereavement on health

Marris (Marris, 1958) Hobson, (1964) and Parkes (Parkes, 1964a, 1970) were some of the first British researchers to provide an account of the impact of widowhood on health. They set the scene for future research to identify bereavement related health problems. The first two will be presented here and work of Parkes later in the second section of this review.

Marris (1958) interviewed 72 widows aged 25 – 56 years (average 41 years 10 months) about a variety of factors related to widowhood. The interviews took place several years after the death of the husband and were part of a series of studies into working class family life in the East End of London. When questioned, 31 (43%) of widows reported a deterioration in their perceived health since the death of their husband. Marris reported that '*many suffered from physical symptoms which, in their opinion or that of their doctor, were caused or aggravated by the shock of their husband's death*' (Marris, 1958: p 13). These problems included: loss of weight; rheumatism and fibrositis; asthma, bronchitis and cramping pains in the chest; recurrence of duodenal ulcers, gastric ulcers, indigestion; swollen feet and ulcers of the legs; falling hair, skin irritation and rashes; abscess of the gum; headaches, dizziness and 'nerves'. The commonest complaint was difficulty with sleeping at least for several months after the death, which was reported by 57 (79%) of the interviewees. Sleep disturbance can also be associated with a number of physical and mental health problems including pain, depression and anxiety.

As an undergraduate piece of research Hobson, (1964) studied the 'widows of Blackton', an anonymised market town in the Midlands. She carried out a series of semi-structured interviews with 40 unselected widows aged 25 to 58 who had been bereaved between six months to 4 years. The main focus of the research was on the financial and social changes experienced by the widows. However, the study does report some of the health problems experienced by the widows, which were believed to be caused or exacerbated by the deaths of their husbands. Hobson reported that the most common complaint was insomnia, especially during the first few months following the husband's death, which was often coupled with 'poor nerves,' headaches and tiredness. All reported some health disorders and 17 reported lasting ill health, which they attributed to their reaction to their husband's death.

Although the impact of widowhood on health was identified, one must be cautious about extrapolating the findings from such studies to a modern day primary care population. In the study by Marris the sample frame was designed to be comparable to previous research in the same area and one criterion for selection was the age of the deceased husband. In that sense the population was targeted, the sample size was relatively small, and the lack of inclusion of widowers means the findings can only be applied to widows. Both studies were limited in their area of selection (East London, Midlands) and all of the widows were young compared to today's widowed population. Data were collected through interviews with the widows and many took place several years after the death of their husbands. This method relies heavily on both memory of events and honesty in volunteering the information. Financial hardship was a particular concern, but since their publication there have been many changes in the financial situation of widows, not least company pensions and life insurance to name but two.

2.3.2 Bereavement as a stressor in general health problems

As described above, bereavement has been associated with a risk of developing a number of health problems which may precipitate consultations with a GP. This research has used the stress model of life events and illness and identified bereavement as one psychosocial stressor. In the case of gastric ulcers, the findings are inconclusive but several studies have reported both an increased risk of developing gastric ulcers and an exacerbation of the symptoms (e.g. dyspepsia) in those widowed, separated or divorced (Talley et al, 1987) which may reflect long term chronic psychosocial difficulties. Bereavement has been suggested as a potential stressor for the onset of skin conditions such as psoriasis (Al'Abadie, et al, 1994), and in a community-based study of 3811 persons aged 65 years and older, Cook et al (1989) reported the age- and sex-adjusted prevalence of 'any' headache was strongly associated with factors including bereavement, depression, and pain.

Low mood has also been found to be associated with increased pain in people with chronic pain in the community from conditions such as arthritis (Alpay and Cassem, 1999). In one study, a key determinant of chronic pain was reported to be bereavement (Walker et al, 1990). There has been much research into the impact of stress on the endocrine system. Some researchers have attempted to measure neuroendocrine changes following specific life events such as bereavement, and there has been speculation into bereavement and loss being a potential aetiological factor in the development of Grave's disease, particularly in children. However much of the work has focused on acute grief rather than long-term bereavement and examined links between psychiatric disorders such as depression and anxiety (generalised anxiety disorder, post traumatic stress disorder, panic disorder) and changes in endocrine function; for example the hypersecretion of cortisol. This area has been reviewed by Kim and Jacobs, (1999) and in general the findings are somewhat inconclusive. Although neuroendocrine abnormalities have been found in many studies, these have not been predictive of long-term health status or psychological outcomes.

2.3.3 The impact of bereavement on diet

Poor diet is a contributory factor to poor health and as such is of concern to the primary care team. Eating has a biological, psychological and social component and many bereaved people report gastro-intestinal disturbances, loss of appetite and loss of weight (Marris, 1958; Hobson, 1964; Madison and Viola, 1968; Parkes, 1964 b; Parkes and Weis, 1983). For those who are elderly and widowed, there may be additional problems about shopping, and cooking for one person which in turn may reduce nutritional intake, putting some at risk of poor health or even malnutrition (Browne et al, 1997; Thomas and Gill, 1998; Wylie et al, 1999). In one comparison of older widowed people to married matched controls it was reported that widows had poorer eating behaviours, which were greatest in those with unresolved grief (Rosenbloom and Whittington, 1993).

2.3.4 Depression following bereavement

Freud originally described the differences between mourning and melancholia (depression), which has been influential on the Western concept of normal and abnormal grieving (Freud, 1917). The key difference is that depression is perceived as a clinical condition subject to diagnosis and treatment, while in most Western cultures symptoms of grief are accepted as a normal reaction to bereavement and not ordinarily treated. The focus of my literature search in this section is mental health problems following bereavement from the primary care perspective. It is the existence of the condition that is paramount. Therefore the question of whether the depression was caused by the bereavement or was an underlying condition exacerbated by the bereavement is viewed as somewhat academic.

There are a number of publications on the prevalence of depression following spousal bereavement from North America, Australia, Canada and the UK. A selection of key articles and a synopsis of their findings are shown in Table 2.3. Overall the evidence suggests that bereavement increases the risk of mental health problems, particularly depression and anxiety (Zisook and Schucter, 1991; Mendes-de Leon et al, 1994; Jacobs et al, 1990). However, there were some methodological concerns with much of the earlier bereavement research, including small samples (Parkes, 1964a; Parkes, 1970; Green et al, 1992), selective recruitment methods leading to potentially biased samples, gender specific recruitment (Parkes, 1964a; Maddison & Viola, 1968; Parkes, 1970; Tudiver, 1991; Avis, 1991; Harlow et al, 1991), an over representation of women and spousal bereavement, non-valid outcome measures, a lack of comparable controls and high rates of drop-out at follow up.

Most studies have reported that symptoms of anxiety and depression generally peak during the first six months of bereavement and improve from the sixth month, with the majority of people being comparable to their pre-bereavement state after the first year (Bornstein et al1973, Clayton 1972; Jacobs, 1989; Zisook and Schucter, 1991; Harlow et al 1991; Hays, 1991). Some bereaved people develop health impairing behaviour patterns such as increased substance use (Stroebe and Stroebe 1994), typically of alcohol, tobacco and psychotropic drugs (Parkes and Brown, 1972), which can have negative consequences for mental and physical health. Severe complications of bereavement include substance abuse, depression, suicide, anxiety and post traumatic stress disorder (PTSD).

Zisook and Schucter, (1991), measured the frequency of depressive syndromes after the death of a spouse and compared them to a married control group. In those bereaved the percentage who met criteria for depressive episodes was 24% at two months, 23% at seven months and 16% at 13 months. The prevalence in the control group was 4%. Factors that predicted depression were younger age, a past history of major depression and still grieving two months after the loss. Being a younger widow appears to be a risk factor for prolonged depressive reaction and increased risk of other mental health problems. However, about a third of widowed elderly people met criteria for a major depressive episode one month after the loss and a quarter two to seven months after the loss (Clayton et al 1972; Jacobs et al 1989).

Mendes-de Leon et al (1994) carried out a prospective study of 1046 elderly people married at baseline, of which 139 were widowed during the three-year follow-up. Those who had been bereaved for six months or less had a 75% increase in depressive symptoms. Most returned to baseline levels by the second year of bereavement. However, young-old widows (defined as 65 to 74 years old) showed increased levels of depressive symptoms into the second and third year of bereavement. This was a risk factor for developing chronic depression following bereavement.

2.3.5 Bereavement studies in the UK

Bebbington (1987) analysed data from English National statistics (1982-85) to assess the association between sex, marital status and first admission to psychiatric hospital. Overall first time admission rates for all depressive disorders were highest in widowed (followed by divorced) patients irrespective of gender, although the rates for women were slightly higher. Marriage appeared to be less protective for women than men. Those widowed earlier (less than 54 years) had the highest first time admission for all affective disorders combined. Several other UK studies have reported an increase in depressive symptoms following bereavement (Parkes, 1964a; Crisp, 1972; Green et al, 1992;

Surtees, 1995; Charlton et al, 2001), although each had specific deficits in their methods, making it difficult to extrapolate to the wider UK primary care population. The evidence suggests that little is known about the true range of mental health problems in the UK bereaved population outside selected groups in specialised settings.

Table 2.3 Depression following bereavement

Authors	Subjects	Country	Depression outcome and Comments
Parkes (1964a) The Case Note Study	Spousal bereavement Women only (N=44)	UK	Examined GP notes of 44 Widows aged between 38-81 years (mean 60.2) No controls, potential selection bias. **Outcome:** Evidence that younger widows (<65), showed significant increase in consultations for psychiatric problems in the first six-months mainly anxiety, depression, insomnia, tiredness, 'run-down', or attendance for tonics and sedation.
Maddison & Viola (1968)	Spousal bereavement Women only (N=375) 132 = Boston USA 243 = Sidney Australia	USA & Australia	Assessed deterioration in health of widows in the year following bereavement compared to control groups. Used a non-validated self reported measure of health for past year. **Outcome:** 22.7% of bereaved rated as having symptoms of depression (controls 5.5%)(p<0.001); 12.8% required medical treatment for depression, controls 1% (p<0.001).
Parkes (1970) The London Study	Spousal bereavement Women only (N=22)	UK	22 Widows under 65 (20-65 years, mean 48.8) were interviewed at least 5 times in the first 13 months following bereavement. Study aimed at describing the psychological features of bereavement. No controls, young sample. **Outcome:** At 13 months Parkes own assessment suggests that 3 were depressed and 9 intermittently disturbed and depressed.
Clayton (1972)	Spousal bereavement Men (N=33) Women(N=76)	USA	109 bereaved aged 20-90 (mean 61.5 years). First 36 recruited from obituaries (refusal rate=51%). Remainder recruited from death certificates (36% refusal). No controls, selection bias. Most were interviewed within 30 days of bereavement. Used an unvalidated measure of depression. Subjects had to admit to having a low mood plus further symptoms. **Outcome:** At first month 38 (35%)(36% of women and 33% of men) were depressed.

Table 2.3 (Continued) **Depression following bereavement**

Authors	**Subjects**	**Country**	**Depression outcome and Comments**
Parkes & Brown (1972) The Harvard Study	Spousal bereavement Men (N=19) Women(N=49)	USA	Carried out a series of structured interviews. This study reported outcomes at 14 months post bereavement. Used 68 matched controls. Refusal rate= 51% (N=116), drop out rate 18% (N=40). Unvalidated outcome measure, used a forced choice design, factor analysis used to group 18 questions into a depression score **Outcome:** More depression than controls (p<0.05).
Crisp & Priest (1972)	Mixed bereavement Men (N=64) Women(N=65)	UK	Sub group analysis of those bereaved selected from patients participating in a large screening study of people aged 40-65Years who were registered with a group general practice in South West London (N=777). A questionnaire identified those bereaved in past year: 45 = parents, 8 = spouses, 25 = siblings, 53 = others (some had more than one bereavement). Outcome measures: a standardised measure of neurotic illness (Middlesex Hospital Questionnaire). **Outcome:** Bereaved taken as a whole showed no more neurotic illness than controls.
Bornstein et al (1973) Clayton et al (1974)	Spousal bereavement Men (N=27) Women(N=65)	USA	A follow-up study of Clayton (1972) above carried out at 13 months post bereavement. Drop out rate=16% (N=17) **Outcome:** Overall, at 4 months 25% were depressed, and at 13 months 17% were depressed. At 13 months of the original 38 who were depressed 12 remained depressed and 4 of the original non-depressed group were depressed. 13% remained depressed throughout.
Weissman & Myers (1978)	Mixed bereavement based on a retrospective epidemiological survey of affective disorders	USA	Retrospective study. Used a validated measure of depression (Schedule for Affective Disorder SADS) for symptoms of depression appearing within 3-months following the death of a close relative. **Outcome:** Lifetime prevalence of depressive symptoms of 10.4% (2.7% for men and 16.2% in women: p<0.01)

Table 2.3 (Continued) Depression following bereavement

Authors	Participants	Country	Depression outcome and comments
Gallagher et al 1983	Spousal bereavement Men (N=95) Women(N=104)	USA	Part of a longitudinal study which used a battery of validated self reported measures of psychological distress at 2 months post bereavement (e.g. Becks depression Inventory, BDI). Subjects identified from death certificates and sent a letter. 30 % response rate of which 211 (29%) were eligible. Mean age men =70, women=67. Control group used but possible selection bias. **Outcome:** Using BDI: More depression than controls ($p<0.01$) and women had higher scores than men ($p<0.01$). When gender and sociodemographic variables were controlled the odds of depression were 1.56 for those bereaved compared to the control group.
Jacobs 1989	Spousal bereavement Both Men and women Total = 111	USA	A study of bereaved spouses that assessed for depressions at 6 and 12 months post bereavement. Used a validated measure of depression (20-item Center for Epidemiologic Studies Depression CES-D) Scale and a structured diagnostic schedule for depression: Structured Clinical Interview for the DSM-III (SCID) and Hamilton Rating Scale for Depression (HRSD). No control group. **Outcome**: 32% of bereaved spouses depressed at 6 months and 27% at 12 months, which was more common in widows than widowers. Past personal history of depression and family history of depression did not enhance the risk of depression. Most of cases of depression lasted longer than 1 month.

Table 2.3 (Continued) **Depression following bereavement**

Authors	**Participants**	**Country**	**Depression outcome and comments**
Bruce et al 1990	Spousal bereavement Men (N=15) Women(N=24)	USA	A prospective large scale community sample to assess depressive episodes. of the 1047 married 39 were newly bereaved, all aged 45 years and older. Subjects interviewed at baseline and re-interviewed twice at 6 month intervals. Newly bereaved defined as those whose spouse died during the year between the first and third interview. A validated measure of psychiatric status was used (Diagnostic Interview Schedule DIS) to give a DSM-II diagnosis. **Outcomes**: 30.8% of the bereaved had depression and 61.5% dysphoria compared to 3.2% and 6.2% of the married control group (both $p<0.001$)
Tudiver et al 1991	Spousal bereavement Men only (N=112)	Canada	A study to compare the psychosocial characteristics of new widows and married men. Used a battery of measures including a validated measure of depression (Beck Depression Inventory). Widows had been bereaved 3-12 months. Various sources of recruitment (e.g. media, funeral home, nurse and doctor). Control group matched for age. Variety in time since bereavement. Difficult to generalise to a wider group of widowers. **Outcome**: Widowers had significantly higher rates of depression than controls ($p<0.001$).

Table 2.3 (Continued) Depression following bereavement

Authors	Participants	Country	Depression outcome and comments
Avis et al 1991	Spousal bereavement women only (N=76)	USA	A prospective 5 year longitudinal study of a cohort of 2500 women aged 45-55 at baseline. Telephone interviews carried out every 9 months. During the study 76 of the cohort became widowed. Control group matched for age and time of interviews with bereaved. Unvalidated measure of psychological symptoms not specifically depression. Comparisons made at three times: (1) the interview immediately prior to when widowhood was reported, (2) the interview at which widowhood was reported, (3) the interview immediately following the report of widowhood. Unable to evaluate the effect of time on bereavement. **Outcome**: More widows than controls reported psychological symptoms at interviews 2 (78% vs 50%) and 3 (64% vs 46%). When interviews 2 and 3 were compared to interview 1 there were more reports of psychological symptoms by widows at both interview 2 ($p<0.001$) and 3 ($p<0.01$).

Table 2.3 (Continued) Depression following bereavement

Authors	Participants	Country	Depression outcome and comments
Harlow et al 1991	Spousal bereavement Women only (N=136)	USA	A longitudinal study of the prevalence of depressive symptoms in elderly widowed and married women. 1144 women interviewed at baseline. 136 became widowed were interviewed along with 409 still married controls at 1 ,6, 12, 18, and 24 months post bereavement. Validated measure of depression (Centre for Epidemiological Studies-Depression Scale CES-D), High scores >15 assessed as criteria for depression. High rates of depression at baseline in future widows group may be a potential bias, but was accounted for. **Outcome**: Widows were significantly more depressed at every assessment even baseline (15% vs 6.4%, $p<0.001$). Depression (CESD>15) for widows at assessments was: month 1 = 58.3%, month 6 = 23.4%, month 12 = 17.5%, month 18 = 17.5%, month 24 = 16.4%. At 12 months the proportion of widows with high scores was comparable to pre bereavement (baseline) scores 15% vs 17.5%, therefore only 40% of widows scores was attributable to the bereavement.
Zisook and Schucter (1991)	Spousal bereavement Men (N=101) Women(N=249)	USA	Study to measure rates of depression in the first year after the death of a spouse. Only 14% of sample contacted eventually took part. Potential for bias. Validated measures of depression (DSM III-R, Zung depression rating scale, Hopkins symptom Checklist). Drop out rate 18% between 2 and 13 month assessments. Control group 126 married **Outcome**: Those assessed as depressed: 24% at 2 months, 23% at 7 months, 16% at 13 months. All significantly higher than the control group which was 4% at each assessment. Factors related to depression at 13 months were: being 65 or younger, having a history of depression, being depressed at 2 months and 7 months, and still grieving at 2 months.

Table 2.3 (Continued) Depression following bereavement

Authors	Participants	Country	Depression outcome and comments
Green et al (1992)	Bereaved identified from a large scale prospective study of depression	UK	Subgroup analysis from a large scale prospective study for risk factors in elderly people. A random sample of people aged 65 years and older generated from GP lists. 1070 interviewed using the validated Geriatric Mental State Assessment (GMSA). Cohort followed up at 3 years. At year 3 there were 44 incident cases of depression. **Outcome:** Using log linear modelling risk factors identified for depression were dissatisfaction with life, feelings of loneliness and smoking. But when dissatisfaction with life and smoking were controlled for, being female and bereavement in the 6-months prior to the 3-year interview were significant (Odds ratio: gender = 2, bereavement = 7)
Mendes de leon et al (1994)	Spousal bereavement Men (N=57) Women(N=82)	USA	Subgroup analysis from a large scale prospective longitudinal survey of elderly men and women in New Haven Connecticut. Analysis based on a subset of 139 subjects who were married at baseline. A series of measures were taken during face to face interviews. Depression was assessed using the validated (CES-D) and defined as high if ≥ 20 defining depressive symptoms. **Outcomes**: When combined 37.5% had high DES-D scores at one year post bereavement (compared to 21.9% at baseline). This reduced to 16.7% at two years (compared to 10.6% at baseline). At one year widowers had higher rates with 46.2%, compared with widows 31.6%. Overall depressive symptoms were highest for all bereaved in the first six months. Depression scores remained higher among widows aged 65-74 (termed young-old) over the first two years who may be a group at risk of developing chronic depressive symptoms.

Table 2.3 (Continued) **Depression following bereavement**

<table>
<tr><th>Authors</th><th>Participants</th><th>Country</th><th>Depression outcome and comments</th></tr>
<tr><td>Surtees (1995)</td><td>Spousal bereavement
Women only (N=65)</td><td>UK</td><td>Part of a study exploring the longitudinal relationship between adverse experience and mental health. Three groups of women with different life events: spousal bereavement (65), husband with life threatening myocardial infarction (143), and women seeking protection in women's Aid Refuge following marital violence (32). Validated measure of depression and anxiety (Research Diagnostic criteria). Bereaved sample recruited from 13 GPs in Lothian Region of Scotland. No control group. Bereaved sample interviewed at about between 4-7 weeks post bereavement (which also assessed 6-moths prior to death) and 3-4 months after that.
Outcomes: 14 women met the morbidity criteria at the first 4 week interview, who had not done so in the 4 weeks prior to the death. When the total post bereavement period was taken into account 42.6% fulfilled the criteria for any depressive disorder compared to 9.4% in the 6 months prior to death (p<0.0018); 27.1 had a major depressive disorder compared to 3.1 in the 6-moths prior to death (p<0.0039).</td></tr>
<tr><td>Zisook et al (1997)

Follow up of Zisook and Schucter (1991) See above</td><td>Spousal bereavement
Men (N=101)
Women(N=249)</td><td>USA</td><td>Used same measures as Zisook and Schucter (1991). Cohort followed for 24 months. Outcomes:
<table>
<tr><th>Type of depression</th><th colspan="5">% of subtypes from months 2 - 25</th></tr>
<tr><th></th><th>2</th><th>7</th><th>13</th><th>19</th><th>25</th></tr>
<tr><td>None</td><td>49</td><td>50</td><td>62</td><td>69</td><td>70</td></tr>
<tr><td>Sub syndromal</td><td>11</td><td>13</td><td>10</td><td>10</td><td>11</td></tr>
<tr><td>Minor</td><td>20</td><td>23</td><td>17</td><td>11</td><td>13</td></tr>
<tr><td>Major</td><td>20</td><td>15</td><td>12</td><td>9</td><td>6</td></tr>
</table>
Those with major depression were significantly younger than the other groups (p<0.001). A past history of depression predicts an increased risk of depression following bereavement.</td></tr>
</table>

Table 2.3 (Continued) Depression following bereavement

Authors	Participants	Country	Depression outcome and comments
Charlton et al (2001)	Spousal bereavement Men (N=22) Women(N=78)	UK	A study to evaluate the impact of bereavement on health of bereaved spouses recruited from a village GP practice list in the West Midlands. 122 bereaved patients were identified. The year of bereavement ranged from 1940 to 1999. 100 had their medical records examined (22 were excluded as they were incomplete) for the 12 month period prior to and following bereavement. Mean age 65.9 years. No measures of mental health were used. Consultations and prescriptions were recorded from the GP notes. **Outcomes**: Total consultations increased following bereavement ($p<0.01$). There was a non-significant increase in prescriptions for physical illness and psychological illness.

2.3.6 Suicide and bereavement

There is a clear association between depression and suicide. Following bereavement, there is also an increased risk of suicidal gestures, completed suicide and death from accidents, which may include some misclassified deaths, following the death of a spouse or a parent (Kaprio et al, 1987; Bunch 1972, Bunch et al, 1971; MacMahon and Pugh, 1965). Charlton et al (1995) carried out a case control analysis comparing those who died from suicide and those who died from natural causes for the years 1990-1992. Being widowed or divorced was an important risk factor for suicide. Martikainen and Valkonen (1996) estimated the relative risk (RR) of suicide in the first 6 months following bereavement was 4.09 (95% CI 2.68, 6.24) for men and 3.91 (95% CI 2.3, 6.66) for women. After six months the RR dropped to 1.96 (95% CI 1.49, 2.59) for men and 1.36 (95% CI 0.93, 2) for women. However, Kposowa (2000) examined the effect of marital status on the risk of suicide and reported that those divorced and separated were twice as likely to commit suicide, but being single or widowed had no significant effect on suicide risk.

Most bereavement studies have found a gender bias with younger men being at the greatest risk of suicide (Carter and Glick, 1976; Gove 1972; Helsing et al, 1982; Mergenhagen et al, 1985) although Heikkinen et al (1995) found evidence of an association between widowhood and women aged 60-69. Helsing et al (1982) found the increased risk of suicide to be higher amongst widowed men. When compared to the general population, Mergenhagen et al (1985) found the mortality ratio for suicide in young widowers (45-64) was about four and a half times the rate for married men of similar age. Younger widowers 25-44 years had the highest marital status mortality ratio (MSMR) of 12.28, which is a mortality rate over 12 times greater than married age-matched men. Widows of comparable age had a MSMR of 3.61.

A 12 year follow up study in Washington County USA of 6266 white married and 3486 white widowed persons aged 60 years and older found death rates from suicide to be 28.7 per 100,000 person years for the married and 40.4 for the widowed. There was also a significant effect of gender, with the suicide risk for widowed men estimated to be 3.3 times higher than that for married men, while the risk of suicide for widows and married women was found to be similar (Li, 1995). Several longitudinal studies have found the risk of suicide to be greatest for the period immediately following the loss. MacMahon and Pugh (1965) compared 320 widowed people who had committed suicide to a matched sample of widows who had died from non-suicide causes. They found that although the risk of suicide among the widowed population was generally higher in the first four years, the risk of suicide in the period less than a year was 2.5 times higher, and in the first, second and third years about 1.5 times higher. The risk at four years or more was equal to the comparison group. The age-standardised suicide rate was 3.5 times higher for widowed men than married men. Widows had twice the risk compared to those married. Based on MacMahon and Pugh's findings, Duberstein et al (1998) used the "psychological autopsy" method as a way of distinguishing those who committed suicide more than four years after the death of their spouse compared to those who committed suicide with four years. Although using small numbers, 21 subjects for those who had committed suicide after four years and 14 who had committed suicide under four years, they found those who committed suicide within four years had significantly higher rates of psychiatric treatment, earlier loss or separation from one or both parents, and a non-significant (P=0.07) higher rate of substance abuse.

In summary most studies have reported an increased risk of suicidal gestures, completed suicide and death from accidents following the death of a spouse or a parent (Kaprio et al, 1987; Mergenhagen et al, 1985; Bunch 1972, Bunch et al, 1971; MacMahon and Pugh, 1965). When compared to the general population Mergenhagen et al, (1985) found the mortality ratio for suicide in young widowers (45-64) was about four and a half times the rate for married men of similar age. Most studies have found age and gender difference with younger men being at the greatest risk of suicide (Carter and Glick, 1976; Gove 1972; Li, 1995).

2.3.7 Treatment of bereavement-related depression

Depressive symptoms are frequently seen as a normal part of the grieving process and some clinicians believe that the treatment of the symptoms of bereavement-related depression may interfere with adapting to grief. However, it may also be that in primary care depressive disorders are not recognised; so perhaps it is not surprising that bereavement-related depression tends to be untreated. Zisook et al (1994) found 83% of bereaved spouses who met criteria for major depressive syndrome received no antidepressant medication. They suggest when there is a prolonged grief reaction, of greater than six months which meets the criteria for major or minor depressive disorders then these should be diagnosed and treated as mood disorders (Zisook, 1994).

The antidepressants nortriptyline and paroxetine have been found to be effective in the treatment of bereavement related depression and traumatic grief (Pasternak et al, 1991; Reynolds et al, 1999; Zygmont et al, 1998). Zygmont et al, 1998 found paroxetine to be comparable to nortriptyline but favoured the use of paroxetine for traumatic grief due to the greater safety in overdose. At present there is little supportive evidence for prescribing antidepressant drugs routinely to bereaved people. However, their use is advocated for those with bereavement-related depression and anxiety persisting beyond six months, with impaired function and traumatic grief (Zygmont et al, 1998).

The SSRIs have a number of advantages as the choice of therapy for bereavement-related depression because they have a broad spectrum of efficacy in the treatment of both depressive disorders and anxiety disorders (panic disorder, obsessive compulsive disorder, social phobia and post-traumatic stress disorder), which are seen in bereavement. In addition they are relatively safe in overdose. Unlike tricyclic antidepressants SSRIs have no cardiotoxicity in overdose and the increased risk of death from cardiovascular disease within the first six months of bereavement is an important variable to consider.

2.3.8 Anxiety

Parkes (1998) suggests that anxiety is the most common response to bereavement. In the opening paragraph of '*A grief observed*' C.S Lewis describes the overwhelming feelings of grief he experienced after the death of his wife. "*No one ever told me that grief felt so much like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing*" (CS Lewis, 1961, p 5).

Jacobs et al (1990) found the risk of panic disorder (PD) and generalised anxiety disorder (GAD) in the second six-month period of the year was about double the rate in the first six months of bereavement. The predictors of PD were a past history of panic disorder, while the predictors for GAD were younger age, past history of anxiety disorders and past history of depression. There were also associations with depression and 55.6% who had anxiety disorder also reported a depressive syndrome. All of those with GAD also met the criteria for major depression and 60% of those with PD also met the criteria for depression. Conversely 82.5% of participants with a depressive disorder also met the criteria for at least one anxiety disorder. When depression was diagnosed it was always associated with the diagnosis of GAD.

2.3.9 Substance misuse and bereavement

Glick, et al in their 1974 Harvard study of 68 widows found they consumed more tranquilizers, alcohol and tobacco. Some 'substance' use may be 'self-medication', to improve mood or to reduce anxiety, particularly where tobacco and alcohol are concerned although illicit drugs are sometimes used. Nicotine has antidepressant properties, there is an association between cigarette smoking and depression and smoking cessation can sometimes result in a depressive relapse (Glassman, 1993).

The problems associated with long-term use of benzodiazepines and the availability of safer antidepressant drugs has resulted in a change in the type of prescriptions offered by general practitioners (GPs) to their patients. In one study a fifth of all those referred to a drug abuse programme for withdrawal from dependence on benzodiazepines had started them during bereavement (Hamlin and Hammersley, 1988). In the past, GPs would frequently prescribe diazepam as a means of relieving the pangs of grief, but the fear of addiction has resulted in a more cautious attitude to prescribing benzodiazepines. This has resulted in a shift to antidepressants, particularly those with anxiolytic properties such as the serotonin selective re-uptake inhibitors (SSRIs). However, a recent double-blind, placebo-controlled evaluation of the use of diazepam after recent bereavement, found no evidence of a positive or negative effect of benzodiazepines on the course of bereavement (Warner et al, 2001)

2.3.10 Alcohol misuse and bereavement

Parkes suggests that dependence on alcohol is a real danger after bereavement (Parkes, 1998). In addition there are clear associations between alcohol misuse and mental health problems, including anxiety and depression. There is evidence that widowers increase their consumption of alcohol (Byrne and Raphael 1999; Mor et al, 1986; Clayton and Darvish, 1979), but for most acutely bereaved, particularly men, the quantity may be clinically non-significant (Zisook et al, 1990) and may in most cases be seen as alcohol use (to aid sleep and to take the 'edge' off grief) rather than abuse. The evidence so far does not support the argument that alcohol abuse is a complication of bereavement for the vast majority of acutely bereaved people.

However, excess mortality from alcohol related disorders has been found for widows and widowers (Helsing et al, 1987; Martikainen and Valkonen; 1996; Johnson et al 2000), suggesting that for some bereaved people excessive alcohol consumption is a problem. One large scale cross sectional survey examining cause of death following bereavement found that widowed men aged 45-64 years had an excess mortality from liver cirrhosis nearly six times that of married age-sex matched controls. Widows of comparable age and older widowed men and women (65 years and older) had approximately two and a half times the excess mortality from liver cirrhosis (Mergenhagen et al, 1985).

Hislop et al (1983), in a study of 510 patients with alcoholic liver disease in Scotland and North Eastern England, found single men and widows were susceptible to alcoholic liver disease. Agren and Romelsjo (1992) calculated age standardised rate ratios for mortality in alcoholism, alcohol intoxication and alcohol psychosis ("AAA") and liver cirhosis. Alcohol related mortality was increased amongst the divorced, widows, widowers and never married men.

2.3.11 Traumatic grief

Prigerson and her colleagues have suggested that the symptoms of 'traumatic grief' form a new diagnostic syndrome (worthy of inclusion in DSM-IV), which is distinct from bereavement-related depression and anxiety and PTSD (Prigerson, 1999). Traumatic grief, a development of attachment theory is argued to have two underlying dimensions: *separation distress:* characterised by symptoms such as mistrust and bitterness as a result of the loss, yearning and searching for the deceased, inability to accept the death, and severe emptiness and loneliness occasioned by the death; and *traumatic distress:* characterised by intrusive thoughts about the deceased, avoidance of reminders of the death, upsetting memories of the loss and of the deceased, emotional numbness since the death, upsetting visual hallucinations about the deceased, and disbelief and shock about the death.

2.3.12 Risks of poor outcome

The literature reports a number of risk factors associated with poor outcome in bereavement (Parkes 1990). These are summarized in Table 2.4

Table 2.4 Risk factors associated with poor outcome in bereavement

Circumstances of the death

- Sudden or unexpected death, especially violent death
- Miscarriage, death of baby, child or sibling.
- Deaths resulting from accidents where bereaved may be responsible
- Deaths from murder or involving legal proceedings
- Where a post mortem and inquest is required.

The bereaved person

- Male gender
- Younger age (<65 years)
- Multiple prior bereavements
- A history of mental illness (e.g. depression, anxiety),
- A vulnerable personality
- An ambivalent or dependent relationship with the person who has been lost

Social situation

- Cohabiting partners, same sex partners, extra-marital relationship may result in 'disenfranchised' grief (Doka, 1989).
- Death with a potential social stigma (e.g. Aids, suicide)
- Lack of family and / or social support

2.4 Primary care support for bereaved people: literature review.

This section will focus on the literature relevant to the role of the GP and DN in the provision of bereavement support. The traditional view of the family doctor is of someone who has close links with their patients, with a knowledge of their families from cradle to grave. Anecdotal evidence suggests that some members of the public still perceive the GP as someone who should visit following a family death to offer the bereaved family their condolences and support. Recent decades have seen the development of the GP role and the wider PHCT which has necessitated an expansion of its services particularly the community nurse. Increased social and geographical mobility has also contributed to an increasingly transient society with fewer people remaining in one location throughout their lifetime. The traditional family GP may no longer be applicable to such people.

One development has been the extended role of the DNs in palliative care in the community. However, the increasing elderly population coupled with public expectation from the primary care services, has resulted in ever increasing demands on their limited resources. The role of the members of the PHCT and the services provided has been forced to adapt to these social changes. This literature review will explore the role and practice of GPs and DNs in bereavement support in the community.

2.4.1 Literature search

Two search strategies were used. The first aimed to identify literature about bereavement or grief in primary care. The second to identify literature specific to the role of the DN in bereavement support in the community. The electronic databases selected for searching were Medline, Embase (Excerpta Medica), Cinhal (Cumulative Index to Nursing and Allied Health) and PsychInfo. While there is some overlap in the literature indexed, Medline and Embase predominantly cover published medical literature, while Cinhal and Psychinfo specialise in nursing and psychological literature respectively. These databases would typically cover most of the literature relevant to primary care.

Bereavement / grief and primary care

The first search aimed to be broad and used two main categories:

1. 'bereavement' or 'bereaved' or 'grief'
2. 'primary care' or 'general practice' or 'general practitioner' or 'GP'. The latest search was last carried out on 14th May 2003.

Both categories (1 and 2) were combined and the duplicates removed. The hits (identified articles) are shown in Table 2.5 below. The titles of the articles were downloaded and saved. These were read onscreen and all relevant articles were selected. A final list of relevant articles was printed and each of the articles obtained. Articles were excluded if they concentrating on specialised populations (HIV / AIDS, Children, miscarriage or abortion). Some were irrelevant because the term grief was used in a generic sense in some articles and was not related to death or bereavement.

Table 2.5 Search strategy for bereavement in primary care

Data bases searched: CINAHL (1982 - 14th May 2003), EMBASE (1980 – 14th May 2003), MEDLINE (1980 – 14th May 2003), PsycINFO (1872 – 14th May 2003) . Using Ovid technology.

	Search History	Results
1	Bereavement OR bereaved OR grief	22168
2	Primary care OR general practice OR general practitioner OR GP	125030
3	1 AND 2	347
4	remove duplicates from 3	250

Overall the search identified very little published research specific to bereavement support in the community. The selected publications tended to fall into one of the following areas:

a) **Information about bereavement**

- reviews of bereavement theories
- characteristics of bereaved people
- the health impact of bereavement

b) **Information about bereavement support**

- death registers and methods use to inform GPs and the PCHT about patient deaths.
- clinical practice and role of the GP and PCHT in bereavement support.
- developing skills and ways to help the bereaved patient.
- comments about GPs beliefs or attitudes toward bereavement support.
- information about grief.

Key articles were selected if they discussed bereavement support from the GP or primary care perspective. Those selected are discussed below.

2.5 Death registers

GPs need to be aware of patients' deaths if they are to offer bereavement support. In the UK death registration has been a statutory obligation since the Births and Deaths registration act of 1836. Keeping a death register at the practice is one method of documenting patient's deaths and an important means of notifying the practice team of the death. The potential benefits of having an accurate system in place to record deaths are: to achieve better administration, to allow planned support for bereaved people in good time, to act as a stimulus to improve accuracy of death certification, and to form the basis for clinical audit and self education. In addition it provides a means of cancelling booked appointments, to prevent unnecessary upset and to prevent avoidable wasted extra costs. In some cases the record also provides screening and advice for familial conditions.

Neville et al (1987) studied six GP practices in Dundee who recorded information about deaths of patients. Among the 193 patient deaths (71%) that occurred in hospital, information was gathered on how the practice was informed and how long it took to receive an official letter. Of the 193 deaths, 112 (58%) were reported to the GP practice by telephone call. For the remaining 81(42%) the practice was informed through a variety of methods which included the patient's relative or neighbour (n = 5), receiving an official hospital letter (n = 23), from the obituaries of the local newspaper (n = 20), by chance (n = 7), by the police (n = 4), and by unknown methods (n = 2).

A number of studies have assessed methods of developing death registers at GP practices (Berlin et al, 1993; Khunti, 1996; Stacey et al, 1998; Wagstaff 1994). In a study of GPs from Newcastle (161) and Sunderland (144) Stacey (1998) sent each a questionnaire about the sources and use of information about patients' deaths. Death registers were then sent to Newcastle practices while Sunderland practices acted as a control group. The results of this first survey were then published by Wagstaff et al (1994) (see below). After two years a repeat questionnaire was sent to both groups of practices. The Newcastle questionnaire also contained additional questions about the use made of the register. Telephone interviews were also carried out with the practice managers. The general findings were that death registers were valued and have demonstrable benefits with regard to administration, bereavement care and medical audit.

Wagstaff (1994), found that GPs usually first learnt about their patient's death from hospital discharge summaries (54%) and patients' relatives (46%) and less commonly from newspaper obituary columns (20%) and hospital telephone calls (9%). The authors argued that current information systems for handling the recording of deaths in primary care were inadequate. Carter (1998) suggested the important topic of bereavement still has a low priority on the curriculum for under/postgraduate and post-registration training. She suggested good communication between professionals is an essential aspect of the care of the bereaved and shared team decision making would enable assessments of individual risks after bereavement and allow care to be individually tailored to needs. Clinical audit and death registers were identified as the ways of improving the quality of care for patients.

2.6 Bereavement support from the primary care perspective

GP consultations

There is evidence for an increase in GP consultations following bereavement (Parkes, 1964a; Mor et al, 1986; Tudiver et al, 1995; Charlton et al, 2001) with most related to mental health problems particularly insomnia, depression or anxiety. A Canadian study of patterns of health care by widowers found visit rates to family physician and specialists rose significantly from the time of the loss compared to married matched controls (Tudiver et al, 1995). Some who have cared for the deceased person in the later stages of a terminal illness may have neglected their own health during that time and now seek help for their problem. Some may develop emotional or mental health problems or use the opportunity to talk to their GP to alleviate loneliness. However, any increase in GP consultation following bereavement has major cost and resource implications for the primary care services. The evidence suggests that older widows are more likely to consult GPs with physical health problems, while younger widows consult with mental health problems. At present there has been scant research into possible interventions to identify and reduce post bereavement consultation although.

2.6.1 Colin Murray Parkes

Colin Murray Parkes carried out a series of investigations to describe physical and mental changes following spousal bereavement. The key studies became known as The Case Note Study (Parkes, 1964a), The London Study (Parkes, 1970), The Bethlem Study (Parkes, 1964b) and The Harvard Study (Parkes, and Brown, 1972; Glick et al, 1974; Parkes and Weiss, 1983).

In the case note study Parkes (1964a) examined the medical records of 44 unselected London widows aged between 38-81 years (mean 60.2) and compared their medical records 2 years prior to bereavement and 18 months post bereavement. The main measure used was consultations with the GP per six-month period. For the pre-bereavement control period the two years prior to bereavement were used excluding the six months immediately prior to bereavement, as this period may have reflected an increase in consultation specifically due to changes in their husbands' illness. The post bereavement 18 months was the 'key' period and was likewise analysed in six-month periods. The reason for the consultation (symptoms) or treatment provided was identified from the notes and classified in one of eight subgroups, namely, psychiatric, hypertension, rheumatism (including other muscular and joint affection), upper respiratory infections, bronchial affections, gastrointestinal affections, skin rashes, and non-respiratory infections.

When all causes were taken together there was evidence to suggest a post-bereavement increase in GP consultation for all causes. Prior to widowhood the average consultation per six month period were 2.2 GP visits, but six months after the death this had significantly increased to 3.6 GP visits, reflecting an increase of 63%, which involved 75% of the widows. Thereafter it fell to 2.6 and increased slightly to 3 GP visits in the second and third six-month period respectively.

Parkes suggests that 'In general it will be seen that there is a rise in the number of consultations for psychiatric and chronic conditions such as osteoarthritis and rheumatism, while the number for acute conditions such as infections and gastro-intestinal disorders shows little change' (page 276).

In his subgroup analysis Parkes looked at younger widows (those under 65 years) compared to older widows (those 65 years and over). Overall, there was evidence that following bereavement younger widows, but not older widows, showed a significant increase in consultations for psychiatric problems, mainly anxiety, depression, insomnia, tiredness, 'run-down', or attendance for tonics and sedation. This was most evident in the first six-months where there was a 240% increase. However, older widows, but not younger widows, showed a significant increase in consultations for non-psychiatric symptoms following bereavement.

This was one of the first studies to compare the pre-and post-bereavement medical notes of widows. The findings were based on a small sample of 44 widows, from eight GPs who were known to the author and had helped in previous studies. However, they were also chosen for their ability to keep 'good case records' (page 275), which in itself introduces a potential bias. The GPs who keep good records may be different from those that do not, both in their approach to medicine and their patients, which may 'attract' certain patients.

In the Harvard study Parkes and colleagues carried out a series of structured interviews with 68 conjugally bereaved people (49 widows and 19 widowers) living in Boston (USA). A number of publications have described its findings (Parkes, and Brown, 1972; Glick et al, 1974; Parkes, 1976; Parkes and Weiss, 1983; Parkes 1998). Parkes and Weiss (1983) state the group were followed up three times: at three weeks, five weeks, and 13 months, post bereavement. A reliability check (visit four) was carried out shortly after the third visit by a different interviewer and finally a fifth follow-up was completed two to four years post bereavement. The bereaved cohort was also compared to a control group matched for age, sex, area of residence, family size, nationality and occupational class. Measurements were made to assess a variety of symptoms and attitudes, which included some from validated questionnaires e.g. Hamilton's Somatic Anxiety Scale (Hamilton, 1959).

The sample was originally derived from death notifications for all married men and women in Boston and Cambridge (USA) under the age of 45 who had lost their spouses between October 1964 and March 1967. Although the figures are presented differently by Parkes and Brown (1972), Glick et al (1974) and Parkes and Weiss (1983) report that the total number of names received were 231 widows and 118 widowers (n = 349), out of which 191 widows and 83 widowers were contacted. Out of those contacted only 49 widows (26%) and 19 widowers (23%) eventually completed the three interviews, which amounted to 21% of widows and 16% of widowers from the original sample of 349 names received. Only 43 widows (19%) and 16 widowers (14%) from the original sample completed the final follow-up interview.

The authors reported that there was no difference between bereaved and non-bereaved people in their consultations with a doctor, implying there was no evidence of any increase in health problems requiring doctors' advice. One plausible explanation for the lack of increased GP consultation was the drop in income in a country (USA) whose health care system requires payment if not covered by insurance. By contrast, Parkes (1964 a) reported that widows in the UK, where the National Health Service enables GP consultation free at the point of access, showed an 80% increase in GP consultations during the first six months following bereavement.

However, significantly more bereaved people had been admitted to hospital (12 vs 4 $P<0.05$), and had seen someone in the past year about an emotional problem (e.g. minister, social worker, psychologist or psychiatrist) (19 vs 4 $P<0.001$).
Other findings were that bereaved people reported significantly greater scores for depression, sleep problems, changes in appetite, changes in weight as well as increased smoking, alcohol consumption and the initiation of tranquillizers in the year following bereavement. These indicate an increased risk of poor health in bereaved people, which has implications for primary care services.

The Harvard study has been an influential study, but there are several criticisms that one can make of it. The refusal rate was very high and the authors acknowledge that contacting the widowed sample two weeks after the death was probably the main reason for this. Also one must also question the ethics of contacting bereaved people so close to the death of their spouse. The sample of responders may very well be self-selecting and not adequately represent those who have lost a spouse. The authors did attempt to assess if refusers differed from the consenting sample and efforts were made to contact 41 of them. However, only 32% (13) were identified and compared to responders. Based on this, Parkes suggests that there was no indication that they differed markedly from participants. However, one must be cautious in comparing these 13 initial refusers with the original participants. The numbers are small and this self-selected group only reflects 32% of those selected to be contacted. In fact when one compared this to the original total it only accounts for 11% of that sample and can hardly be seen as representative. Once again differences in the health care system, cultural factors and potential bias in sampling make the findings from this study difficult to extrapolate to a UK primary care population.

2.6.2 Features of grief in a bereaved population from a general practice

Levy and Balfour Sclare (1976) carried out a study of bereavement in one of the author's general practice, which they described as being within an underprivileged, working class district of Glasgow. The aim was to gain information about the reaction to bereavement in an unselected population. Within the practice there were 58 deaths in a 12 month period of which 26 had no available relatives. Of the 36 deceased patients there were 46 bereaved relatives who were on the practice list and had lived with the deceased: 14

daughters, 10 wives, 7 husbands, 5 mothers, 5 sons, 1 father, 1 brother, 1 son-in-law, 1 female cousin, and 1 grandson.

The method employed was a semi-structured interview carried out by the family doctor within the 4 to 8 week period following bereavement. The authors describe a number of psychological features of the grief reported by the bereaved people including depression by 80.4%, loneliness 65%, sleep disturbance 63%. A follow up interview 12 months later on 39 of the original sample found that eight (21%) of them remained in a state of severe grief. However, how this was defined remains unclear. Changes in health related behaviours were also reported. Of the 24 smokers 18 (75%) had increased their consumption of tobacco and of the 35 who drank alcohol 10 (29%) had increased their consumption since the death.

This is an interesting article written from a medical perspective, with the aim of describing the features of grief in a bereaved population from a general practice. However, there are two main criticisms one can level at this research. Firstly, the population sample was small (46) and comprised a variety of different relatives making it difficult to generalise any particular features to a specific bereaved population (e.g. spouses). Secondly, little information is provided about how diagnostic decisions were made about the bereaved people (e.g. depressed mood) other than it was obtained from the interview. It was interesting to note that the authors concluded by suggesting an important role for the GP, Community Nurse and others in bereavement support.

> *'There is clearly a professional role for the doctor in helping the bereaved by means of support, counselling, and occasionally medication. His (sic) effectiveness is likely to be enhanced when he has had an opportunity of establishing a professional relationship with the individual before the bereavement. The clergy, the social worker and community nurse may also be of great assistance to the bereaved.'* (Levy and Balfour Sclare, 1976: p336).

2.6.3 GPs and the widowed elderly

Cartwright (1982) reported a study to assess the role of the GP in helping the widowed elderly. She interviewed 361 widows and widowers identified from the death register and visited four to seven months post bereavement. A higher proportion of widowers agreed to be interviewed (83% vs. 70% of widows). In addition she interviewed a number of GPs. All doctors were sent a questionnaire and in addition patients were asked for permission to contact their GPs about their receipt of advice on health and treatment. For both widows and widowers the main supporters identified were their daughters, who offered most comfort and most practical help.

When GPs were questioned about what they should do when an elderly patient was widowed, 41% stated that they should visit the widowed at home, 36% said it would depend on the circumstances, 15% that they should respond to direct request for help, and 8% would contact the widow by letter or telephone to see if she needed help. However, for those 41% of doctors who said they should visit bereaved people, the actual experiences of widows / widowers showed that less than half of those doctors (45%) had actually carried out a visit to the home, demonstrating that they did not always carry out what they advocated as best practice.

Only a minority of those widowed had any contact with a GP before their spouse's funeral, although by four to seven months three quarters had had some contact with a GP. Health problems reported at that time included: sleeplessness, 'nerves' or depression and forgetfulness or confusion, many of which had become worse or developed since the death of the spouse. A comparison of patients' reporting of problems and GP-completed questionnaires about the patients revealed that there was a great deal of underreporting to GPs and GPs were often not aware of the problems. In addition many patients also had problems with activities and about a fifth had problems with going out or using public transport.

2.6.4 Audits of bereavement support in GP practice

Blyth (1990) carried out an audit of terminal care in a GP training practice and found all those bereaved were visited at least once in the year for counselling. He also revealed that 23 out of 34 bereaved people felt that bereavement counselling from a GP was not necessary. In response Gunnell (1990) suggested that in his experience, visiting bereaved families was not usually offered by GPs. Gunnell also reported his small study of 31 bereaved people in a general practice in Weston Super Mare. Six to 12 months after the deaths only nine (29%) had any record of the bereavement in their notes. Based on his interview with 10 bereaved patients, eight out of ten stated that GPs should visit after bereavement.

Daniels (1994) evaluated the role of the GP in bereavement care. The study aimed to evaluate three key areas: communication about patients' deaths, the action taken by GPs on hearing of a patient's death, and the role of the GP in bereavement support as perceived by those bereaved. The study comprised both an evaluation of the GP records and a postal questionnaire and telephone interview with first degree relatives of the bereaved.

The author retrospectively analysed all deaths from Jan to Aug 1991 at an inner London practice with three partners and 5500 patients. He recorded information from patients' records and telephone message books and detailed place and date of death and date and method of notification of the hospital deaths (letter, phone or relative). In total 35 deaths occurred within the eight month period. Twenty eight deaths occurred within local hospitals, five at home, one in surgery and one abroad. In addition Daniels identified the first degree relatives of the 35 deceased patients. Of those, six had no next of kin, seven were not registered at the practice, and four were excluded due to being out of contact or too upset to participate. A total of 18 bereaved relatives were contacted at least three months post bereavement and all agreed to participate. Eleven were wives with an average age of 67.5. The relationship of the others was not described. Each was sent a postal questionnaire and later followed up by a 30-40 minute interview.

Daniels found that the notifications about patients deaths to GPs from hospitals was varied; while the hospice unit telephoned and wrote to the GP on the day of the death, of the 28 hospital deaths, only 13 (46%) were notified within two days, five (18%) were notified between 10 – 14 days, three (12%) took over a month, and 7 (25%) of deaths were never notified to the GP. In eight cases the referral was so late that the bereaved person informed the GP themselves.

Based on the data from the questionnaire and phone interview with those bereaved, Daniels identified loneliness, financial worries and sleep problems as concerns most likely to be mentioned. When asked about what would have been appreciated in helping in their bereavement 16 (89%) felt some acknowledgement from their GP would have been a great help and 10 (56%) stated it would have been 'eased' by a visit. Ten said it would have been helpful to talk to someone apart from their friends and family and the GP was the one professional most mentioned. The evidence suggests that the majority of bereaved felt that the GP had a key role to play during bereavement.

It was reported that in 13 cases there was contact from the GP, but only one person was visited and the remaining 12 told to contact the GP if they needed help. The study highlighted that in addition to their social networks, people perceived their GP as an important source of support and care during bereavement. The author makes two key suggestions: the need for hospitals to improve their notification of deaths to GPs and for GPs to have a protocol for the care of the bereaved which should include an initial contact procedure, an at-risk assessment, an assessment of need including financial difficulties, and a follow-up procedure.

2.6.5 Bereavement protocols

Charlton and Dolman (1995) argued that even though bereavement does not fit the medical model of disease, it is a medical problem as there is a resultant morbidity and increased mortality associated with the surviving relatives. To this end they proposed a bereavement protocol which could minimise the effects of bereavement. They further suggested that general practice offers an ideal opportunity to support bereaved people. They made a number of suggestions about ways to develop bereavement support including:

- that all staff, including undergraduates and post-graduates familiarise themselves with the protocol
- regular audit to ensure quality is maintained and improved
- sending a condolence letter and the provision of information to bereaved patients at the practice
- the development of a practice death register
- recording dates of birth, death and pertinent anniversaries relating to the deceased patient in the case notes of the bereaved relatives and intimates

- the allocation of a key worker from the PHCT to facilitate bereavement support and provide a focal care point for those bereaved
- monitoring and reviewing bereaved people over time

However, in response to the article by Charlton and Dolman (1995) Woof and Carter (1995) questioned the advisability of adopting such protocols unreservedly, without justifying evidence, and called for further research into bereavement support, particularly in evaluating any proposed innovations.

2.6.6 Audit of referral to secondary care

Lloyd-Williams (1995) carried out an audit of bereavement related referrals to a psychiatric service for a three month period. Of the 12 referrals, eight (67%) had visited their GP on two occasions prior to the referral, three had visited on one occasions and one had in excess of 30 consultations. Only one patient had been offered bereavement support from the GP or PHCT. The psychiatric services identified 'abnormal' grief in two patients, while eight were referred to Cruse counselling service and two to a specialised local counselling service for those who had lost a child. It was interesting to note that the interval between bereavement and referral ranged from 2 months to 10 years, but 10 had been referred within the year with a mean of 4.3 months.

Although a small study the author makes three valuable points. Firstly, the GP and PHCT need to be more aware of the normal grieving process. Secondly, there needs to be increased provision of support for bereaved people and lastly, that bereaved people are made more aware of bereavement services such as Cruse and local voluntary agencies. Improved education for the PHCT and better provision of information to bereaved people would help to address some of these concerns and need to be evaluated.

2.6.7 The current state of bereavement support in primary care

Woof (1997) provided a discussion paper of bereavement care in British general practice and suggested that at present it was unclear what support GPs should offer their bereaved patients as there are no formalised models of bereavement care. Most studies only quantify the level of GP contact without indicating the quality or benefit of this contact. This argument was further developed by Woof and Carter (1997a & 1997b), who contributed a well written two part literature review of bereavement in general practice. In the first article (1997a), they briefly explored some of the psychological theories of bereavement in particular the work of Freud (1917), Lindermann (1944), Parkes (1972), Bowlby (1980), Stroebe (1994), and Walter (1996). They also summarise some of the literature that had evaluated the impact of bereavement on mortality and morbidity with a particular focus on depression. The second article (1997b), builds on the first and provides a review of the literature debating normal and abnormal bereavement and risk factors for poor outcome. It also provides a systematic review of bereavement interventions and offers suggestions for bereavement support in primary care. The general practical recommendations suggested by Woof and Carter (1997b) were:

- Developing efficient means of notifying the PHCT of patients deaths
- Routinely recording the death in the notes of those bereaved
- Sending a letter of condolence to those bereaved
- The provision of information about grief and the services available
- The provision of practical advice
- A bereavement visit soon after the death
- The use of risk assessment in planning care
- A follow-up visit 6-10 weeks following the death
- Developing links between the PHCT and bereavement services
- The provision of professional bereavement counselling within the practice
- A psychologist-led group bereavement service within the practice.

The two articles make a substantial contribution to the literature on bereavement support from the GP perspective. Although the focus was mainly upon GPs one criticism that could be levelled at the review is the limited reference to the wider PHCT, particularly the DN service who frequently provide palliative care and bereavement support. This will be discussed later.

2.6.8 A survey of GP practice in bereavement support

Harris and Kendrick (1998) carried out a survey of the senior partners of 500 General Practices in South Thames Health Region, achieving a 71% response rate. Hospitals were perceived to be significantly slower than hospices in notifying practices of patient deaths, within the first 24 hours ($P<0.0001$). A death register was kept by 196 (56%) of the practices, while 230 (65%) discussed deaths together in the practice and 142 (40%) identified bereaved relatives. When it came to bereavement support 137 (39%) said they routinely offered bereaved relatives contact with a PHCT member while 133 (38%) supported only those who asked for help. Factors associated with providing routine support included keeping a death register, discussing deaths together, identifying bereaved relatives, and having a special interest in palliative care. In addition, 61 responders wrote comments which were analysed and themes identified. The key themes reported were: the importance of the multidisciplinary nature of bereavement care (14 comments), time and workload restraints (9 comments), the importance of personal care (10 comments), the dilemma of whether to provide routine care (6 comments) or selective care (10 comments), and the danger of over-medicalising the grief process (4 comments). Examples of each theme were provided.

This was a useful study which identified bereavement support from a GP perspective. However, the study has a number of limitations. Firstly, there is a danger of bias as the sample comprised senior partners in general practices in the South Thames Health Region, who may have specific views about bereavement support which their colleagues may not share. Similarly although a large sample with a good response rate (71%), the respondents were specific to the South East of England and may not reflect the views of a the wider UK GP population, which limits the generalisability of the findings. Also no information was obtained about bereaved peoples' needs or their views about the role of the GP in bereavement support. This would have been useful to compare the GPs practice and views with the expectations of the bereaved people at those practices.

2.6.9 Qualitative research involving GPs or bereaved people

An interesting and informative assessment of bereavement care in general practice was carried out by Pearce (1996). Using a qualitative research design she carried out a series of audio-taped, semi-structured interviews with 12 GPs and 15 recently bereaved people to examine the process of bereavement care from both perspectives. Some of the key findings are discussed in brief.

From the GP perspective she ascertained that GPs felt that bereavement support was an important and necessary part of their work, and that when the GP had formed a long-standing relationship with their patients it enabled them to have a 'special' role in bereavement support distinct from other caring professionals. Background knowledge of the social situation of bereaved patients was perceived as important. Where GPs had provided palliative care for the deceased patient, some described feeling a sense of guilt if events leading to the patient's death had not run smoothly. This was particularly so when pain relief had been inadequate. GPs described how with some patients there was the danger of developing 'over-dependence' on their support, which was described as problematic for some. Several GPs described how they used medical problems (e.g. raised blood pressure, or diabetes) as an excuse to follow up bereaved patients who they were concerned about, particularly when depressed or lonely. This appeared to legitimise the GP maintaining regular contact with the patient. The provision of bereavement support varied between GPs and of the 12 interviewed, none reported having or using either a personal or practice policy for contacting or dealing with bereaved people. Lack of time was reported by 11 (92%) of GPs as a major problem when it came to dealing with bereavement. Only one GP described as proactive routinely mentioned the existence of support agencies (e.g. Cruse), the others responded to patients' needs if they felt unable to cope with patients' needs. Pearce reported that most GPs had received little training in the management of bereavement although most felt at least moderately confident in dealing with it, although each had developed their own style. Personal experiences had helped some of the GPs to develop an awareness and understanding of bereavement needs. The importance of the DN role in bereavement visiting was praised by most of the GPs who described them as forming an essential support link with bereaved people once the funeral was over, and family gone home leaving the bereaved person alone.

From her interviews with the 15 bereaved people Pearce, identified key themes, some of which will be reported below. The pre-death relationship with the GP was identified as important and most bereaved people reported their satisfaction with the care provided. However, the way that the GP carried out the task of breaking bad news was an important matter that could seriously affect the pre-death relationship. Although bad news was usually told in the hospital, it was sometimes left to the GP. Similarly, communication within the general practice was seen as important to ensure crucial information was conveyed to other members of the PHCT. In all but one bereaved person, the initial contact with the GP was made within the first few weeks. This was appreciated by most bereaved people, as it provided an opportunity for many to talk about issues related to the death to a 'friendly face', although some of those interviewed were not satisfied with the way the GP had dealt with them after the death. Pearce reported that the DNs were highly praised for their role in bereavement visiting and the support in the early weeks, by all interviewees who had been in the situation to receive DN care for the deceased person prior to death. The perceived role of the GP in bereavement support remained somewhat unclear. Pearce suggested that most agreed it was special role, but few of those interviewed provided a definition of the characteristics of such a role.

In summary this was an interesting and novel piece of research which used a qualitative method. It also identified the variety of practice and views about the methods employed in bereavement support.

Saunderson and Ridsdale (1999) reported a qualitative study using a grounded theory approach designed to explore the beliefs and attitudes of general practitioners to death and bereavement among their practice population. From an initial list of 118 GPs located in the area of Redbridge and Waltham Forest Family Health Authority GPs, 45 were chosen purposefully to provide rich data. Of those, 25 (56%) agreed to participate in an audio-taped semi-structured interview. The tapes were transcribed and the data analysed for themes. Five themes were identified which indicated the general concerns voiced by the GPs namely: GPs fears of making mistakes, different approaches in hospital and in general practice, effect of medical training versus personal experience of life, doctors' different approaches towards contacting the bereaved, the doctor's own sense of loss.

Of the 25 GPs interviewed, 17 (68%) specifically discussed making contact which was associated with the doctor patient relationship; that is the stronger the relationship the more likely they were to initiate contact. However, in unexpected or traumatic deaths they were sometimes more likely to make contact. Twenty two (88%) of the GPs reported that vocational training had little impact on their management of bereavement. Their beliefs and attitudes were based on personal experiences, and socio-cultural and religious beliefs rather than professional training. Twenty (80%) of the GPs reported a perceived difference between medical management in the hospital and general practice. While hospital medicine focused on acute serious diseases requiring rapid diagnosis, patients presenting to the GPs were perceived as having ‘softer’ medical problems with diagnostic uncertainty requiring the GP to differentiate physical from psychological diagnosis. The length of time patients were known to the GP enabled a different and closer relationship to be developed.

In contrast to Saunderson and Ridsdale’s research, which focused on bereavement support from the GP perspective, the study by Main (2000) interviewed newly bereaved patients to evaluate the role, value and content of a proposed bereavement protocol to be developed within her general practice. Using a qualitative design which utilised the principle of grounded theory, she interviewed 23 (six men and 17 women) bereaved people. The article initially outlined the difficulties faced in identifying bereaved people from the practice, which did not have a death register. This was achieved by trawling through the computer list of deaths at the practice in the previous two years, to compile a list which was crosschecked against relatives or partners living at the same address. It provides a useful reminder that a death register would have provided such information immediately. For her method of interview, Main chose not to use any audio-recording, which she suggests would have inhibited participants from taking part and talking openly, rather she made field notes and wrote up the interview afterwards. The data were analysed and themes were identified in each interview and used to inform subsequent interviews in an iterative manner. I would suggest this was probably a mistake and that richer data would have been obtained from audio-taped interviews and tape transcription. However, five key themes were identified, namely satisfaction with the service, quality of information given (GP and hospital), adequacy of communication (GP and hospital), differing expectations of the GP service, and development of the service. Main reported that the majority of bereaved people interviewed felt that contact and communication with newly bereaved people from the GP was an important something that ought to happen.

2.7 District Nurses and bereavement

The literature search described above identified the importance of palliative support and its link with bereavement support in the community. As DNs are the main provider of the palliative support in the community this raised the possible that DNs may perceive bereavement support to be part of their role and may feel be better placed than GPs to undertake bereavement support. However, the role and views of the DN were not clear, and so I decided to carry out a literature search to clarify bereavement support from the DN perspective. A separate literature search was carried out to identify bereavement literature relevant to the District / Community Nurse. The strategy and hits are shown in Table 2.6. The latest search was carried out on 14th May 2003.

Table 2.6 Search strategy for the role of the District Nurse in bereavement support.

Data bases searched: British Nursing Index (1994 – May 2003), CINAHL (1982 - 14th May 2003), EMBASE (1980 – 14th May 2003), MEDLINE (1980 – 14th May 2003), PsycINFO (1872 – 14th May 2003). Using Ovid technology.

	Search History	Results
1	Bereaved or bereavement or grief.	22749
2	Community or district.	315846
3	Nurse or nurses or nursing.	470314
4	2 and 3	31839
5	1 and 4	240
6	Remove duplicates from 5	181

The identified hits and abstracts where possible were saved into the bibliographic data base manager Reference Manager and each title and if possible the abstract was read. Articles were selected to be obtained if they described novel research, or commented on the role of the DN (community nurse) in bereavement support. Although the total number of references identified with the search terms was 181, only a few appeared relevant. Most articles did not present research; rather they were descriptive in nature and aimed at informing nurses about bereavement itself. Articles excluded were those specific to HIV or AIDs, loss during pregnancy (miscarriage or selective abortions), hospice care, or sudden hospital deaths (mainly accident and emergency).

To supplement the literature identified from the databases, I also cross checked the references in the articles obtained, and used other sources such as text books. Using this procedure I identified several other articles which had not been found from the electronic search. One example from the District Nurse search was Bassett & Bassett (1994). This article contained all the required key terms for the search (e.g. nurse and bereavement), yet it failed to be identified. However, when the authors' names were searched, the article appeared. This example demonstrated the potential for error in any electronic literature search, which can only be minimized by cross checking a variety of sources.

Eleven articles were selected and obtained: Abott (1981), Melhuish (1983), Faulkner, (1993), Bassett and Bassett (1994), Monroe and Smith (1997), Mead et al (1997), Lyttle (1998), Grimby (1999), Costello (1995), Koodiaroff (1999), and Lyttle (2001).

Abott (1981) provided a brief comment about potential development of a bereavement support service by Health Visitors (HVs) forming a link between the hospice and community services. Melhuish (1983) reported a small scale study to evaluate the views of eight GPs and nine HVs on the role of the HV in bereavement counselling. It concludes with the suggestion that HVs have a definite role in bereavement counselling, although poor communication between GPs and HVs was highlighted as a factor in their being unaware of patient deaths. Faulkner (1993) provided an overview of the 'facts' surrounding the nature of normal grief and the added complications faced by the elderly. This was a brief paper aimed at providing basic information to a community nurse readership. A similar article was provided by Bassett and Bassett (1994), who looked at the role of the practice nurse when dealing with bereavement. The article is descriptive and provides basic guidelines about dealing with bereaved patients who attend the practice.

Mead et al (1997) presented a review of the literature on primary care nurses' role in dealing with emotional health problems. The article discusses the role of a number of

community nurses including practice nurses, DNs, HVs, midwives, and School nurse. Bereavement was briefly discussed and applied to each particular nurse speciality. However, this article provided little new information for the DN.
The article by Grimby (1999) was a non-English language article (Swedish) although the summary outlined the study in English. In brief this was a study to investigate the impact of nurse led bereavement counselling at one, three and twelve month in the homes of 50 newly widowed elderly people. The results were not described in the English summary.

Three articles provided a discursive personal view of the role of the DN in bereavement support (Costello, 1995; Monroe and Smith, 1997, Koodiaroff 1999). Koodiaroff (1999) writing from an Australian perspective suggested that community nurses were ideally placed to offer bereavement support, when they had provided palliative care. Similarly the other authors proposed that the District Nurse could potentially play a key role in assessing the needs of the bereaved person, helping them with the pain of grief, offering advice, support and information (Costello, 1995; Monroe and Smith, 1997) and helping to prevent any breakdown in health. However, the arguments were mainly based on anecdotal evidence and the personal views of the authors.

Two articles were authored by Lyttle (1998, 2001). However the first article mainly described the challenges he had faced in negotiating the local research ethics committee to carry out research for his MPhil about bereavement visiting. The research subsequently formed the basis of the second article identified. Lyttle (2001) aimed to explore the perceptions of community nurses about delivering bereavement support to older people, and also to understand how older bereaved people perceived the support from the community nurses. To achieve this, he used a semi-structured, audio-taped interview for both nurse and older bereaved people and interviewed 20 nurses and 10 older bereaved people.

Following the interview, Lyttle made extensive notes on the interview data rather than gaining a full transcription. Themes were identified based on frequency of occurrence, which was used to construct a concept map as a summary and aid to identifying the core concepts. This was subsequently sent to the nurses for their approval and to increase validity. It is reported that all agreed with their respective summaries.

Lyttle identified three core concepts for both the nurses and the older bereaved people; community nurses: relationships, practice and organisational issues.
Older bereaved people: relationships, practice, and perceptions of self.
The relationship between the family and the nurse was a key theme identified. The Nurses reported that they rarely made a first visit as a result of bereavement (a cold call) rather it was part of the continuity of care provided to the deceased patient in the terminal stages of their life. This view was also voiced by the bereaved people, who felt the relationship with the nurse was important for their continued support.
Influences on practice reported by the nurses included limited time and resources, personal experiences, and training (knowledge) in bereavement. The bereaved people also reported that nurses were skilled at assessment. The organisation theme identified by Lyttle highlighted the nurses' belief in the importance of delivering a client-led service via the PHCT, which benefited bereaved people if the team worked well together. Lyttle reported that the bereaved people's self perception of their ability to cope was mixed and they valued their own experiences as an indicator of how well they coped. Although a brief paper, it was the only research identified that reported bereavement support from the community nurse perspective and the bereaved person's perspective. In that respect it shared similarities with Pearce (1996) described above.

2.8 Summary

This literature review has identified evidence that bereaved people are at an increased risk of both physical and mental health problems, particularly depression and anxiety. This highlights the important role of the whole primary care team in identifying those at risk and offering effective interventions and treatment. Unfortunately, the literature also suggests that little is known about the extent of practice or role of GP's and DNs in bereavement support in the UK.

Most GPs and bereaved people believed that the GP had an important role in the provision of bereavement support. However, the evidence suggests that even when GPs report that bereavements visits should be carried out, many do not comply with their own advice and do not carry them out. This may be due to the pressures of time and the limited resources at the practice. The function of the primary care team is the detection, diagnosis and treatment of health problems. In addition they also have a role in identifying potential health problems and offering preventive advice, support and treatment. It is therefore important that the primary care team is aware of potential health problems resulting from bereavement, as identification of preventable risk factors may assist in the development of future intervention strategies.

The evidence suggests that palliative support may be the key to successful bereavement support in the community, and therefore development of these services should be in parallel. However, when a death has occurred suddenly or without prior GP or DN contact, little information is known about the provision of bereavement support. This was raised by some authors who commented on the importance of the pre-death relationships between the bereaved person and the PHCT for the successful provision of bereavement support. This is an area that needs further exploration.

The successful provision of bereavement support appears to be most effective when there is effective organisation and communication within the PHCT. Death registers appear to be of key importance in the identification of bereaved people, they also provide the infrastructure to enable information about deaths to be shared with members of the PHCT. Communication between DNs and GPs was an area that needs to be evaluated and promoted.

There is little evidence of any consistency in the practice of bereavement support. GPs remain divided over whether support should be proactive or reactive. They also remain unsure whether there should be a bereavement protocol to promote best practice. The evidence suggests that the DN in collaboration with the GP is key to the provision of successful palliative support in the community. Although, several authors have promoted the idea of DN-led bereavement support in collaboration with the GP, there remains little evidence of what DNs actually do or their perceptions of their role in bereavement support.

Based on my review of the literature pertaining to DNs it was evident that this remained an area in need of research and I decided to address this.

Chapter 3 Methodology

3.1 Introduction.

This chapter will discuss the research methodology used in this thesis. It starts with a brief definition and clarification of key philosophical concepts used in research, namely ontology, epistemology, axiology, methodology, methods and paradigms. It will also justify the use of a mixed methods design and present a discussion about issues of quality pertinent to each methodological framework.

3.2 Epistemology

Epistemological issues are concerned with the origins, nature and limits of human knowledge. This thesis is based in the social sciences and the epistemological questions are about how one can attain knowledge about the social world. A researcher's epistemological position can be described as the researcher's 'theory of knowledge', which underpins their basic belief system about how social phenomena can be 'known' and how knowledge can be generated.

3.3 Ontology

Metaphysics deals with the nature of reality. Ontology is the branch of metaphysics concerned with the study of existence itself. The problems of ontology and epistemology are interlinked, as the researchers' ontological perspective (what they believe to be real and exist) forms the foundations of their epistemological position (how they ask questions of that reality to gain knowledge). Objectivism suggests that there is one real objective world with a single reality, while relativism, suggests multiple subjective realities that are constructed by both the social actor (those observed) and the researcher (the observer) through their joint interaction, perceptions and actions.

3.4 Axiology

Axiology is the branch of philosophy concerned with the study of ethics, aesthetics, and religion, and centres on the role that values play in research inquiry. The positivist perspective proposes that researcher's values are independent from the research and ultimately the findings. This value-free perspective is in contrast to the interpretivist (qualitative) perspective, which argues that subjectivity and values are an inevitable component of the research process and are often desirable.

3.5 Methodology

Methodological considerations are concerned with how knowledge is obtained during the research process; essentially the overall research strategy and techniques to be used to answer the research questions. Methodologies enable the researcher to carry out their research within a particular framework, which defines the particular methods that can be used. Research questions are constructed by the inquirer, who is ultimately grounded within their gendered, social, cultural and experiential perspective, which contributes to their ontological stance.

3.6 Methods

Research methods are the procedures, strategies and tools used within a research methodology and reflect different ways of asking questions. They also define how data should be generated and recorded. However, method is subject to the constraints of the chosen methodological framework.

3.7 Paradigms

Paradigms represent a worldview that encompasses ontological, epistemological, axiological and methodological assumptions. A precise definition is somewhat obscure as the physicist and philosopher Thomas Kuhn, who introduced the term into modern language, used it in no fewer than 21 different ways (Masterman, 1970).

Denzin and Lincoln (2000) suggest paradigms become more complex and interwoven at the level of the specific researcher, within their particular research context. Guba and Lincoln (1994) proposed four alternative paradigms, namely positivist, post-positivist, critical theory and constructivism, later adding a fifth 'participatory paradigm' (Lincoln and Guba, 2000). Guba (1990) suggested that of these, three paradigms have risen to challenge the predominant positivist paradigm, namely post-positivism, critical theory and constructivism.

This doctoral work was carried out within the positivist (quantitative) and constructivist-interpretivist (qualitative) paradigms. When carrying out this doctoral work I was based within the department of primary medical care with a predominantly positivist research bias, and emphasis of research within the medical model of illness and health. This primarily influenced the development of the first study (see chapter 4) which used diagnostic criteria, and the measurement of mental health problems reported by bereaved people. Similarly my second study (see chapter 5) used a postal survey methodology within the positivist approach. However, several primary care researcher colleagues had developed an interest in qualitative research which had resulted in interdepartmental collaboration with health care researchers with specialised skills in qualitative research, one being my supervisor Professor Sheila Payne. Encouraged by both my supervisors and colleagues, I explored the plausibility of using mixed research methodologies within the same doctoral research. Chapter 6 describes a series of audio-taped interviews with DNs, which used qualitative methodology.

Bereavement provides an ideal topic to explore using mixed methodology. It has a socio-cultural aspect and yet many bereaved people present to their GP with medical complaints. From my reading of the literature surrounding grief and bereavement, I found myself constantly shifting between two perspectives; firstly the bio-medical aspect of grief demonstrated by increased rates of depression and other mental health problems and secondly the psycho-social meaning that grief had for both the bereaved person and the health professional dealing with them.

Although I acknowledged that there was fundamental incompatibility in the positivist and interpretivist paradigms I believed that there was nothing wrong with metaphorically ‘stepping into’ the paradigm and seeing the world from that perspective. Therefore my solution was to utilize the strengths of both qualitative and quantitative research from their particular perspectives to address my research questions. In the following, the general principles of each will be outlined and fundamental differences highlighted. It will describe the deductive and inductive reasoning used in the research process.

3.8 Quantitative research

Quantitative research comes within the broad paradigm of positivism, sometimes termed the scientific or conventional paradigm, which emphasises observations, measurements and quantification. Kerlinger (1992) summarises this perspective:

> *"scientific research is systematic, controlled, empirical, and critical investigation of natural phenomena guided by theory and hypotheses about the presumed relations among such phenomena"* (Kerlinger, 1992. p 10).

Researcher objectiveness is important, while subjectivism is avoided or reduced to a minimum. From this epistemological viewpoint, subjective understandings of social actions are not relevant. Values and beliefs held by the researcher are viewed as immaterial to the procedures and outcomes. The implication is that the researcher is independent from the social phenomena or subjects (participants) and has little or no impact upon the findings. The strategies employed within the positivist epistemological perspective are aimed at the researcher controlling the social situation, often under experimental conditions, so that they can objectively measure and quantify the phenomena being studied.

Theories are generated through inductive reasoning (see later) and are designed to predict and explain natural phenomena and also to provide an explanation of observed regularities. A theory can be defined as:

> *'a systematic, abstract explanation of some aspect of reality'*
> (Polit and Hungler, 1999: p 24).

Concepts are the building blocks of theories, and through the integration of concepts and the use of inductive reasoning theories develop. Theories link together the independent variables (IVs) and dependent variables (DVs) in a study.

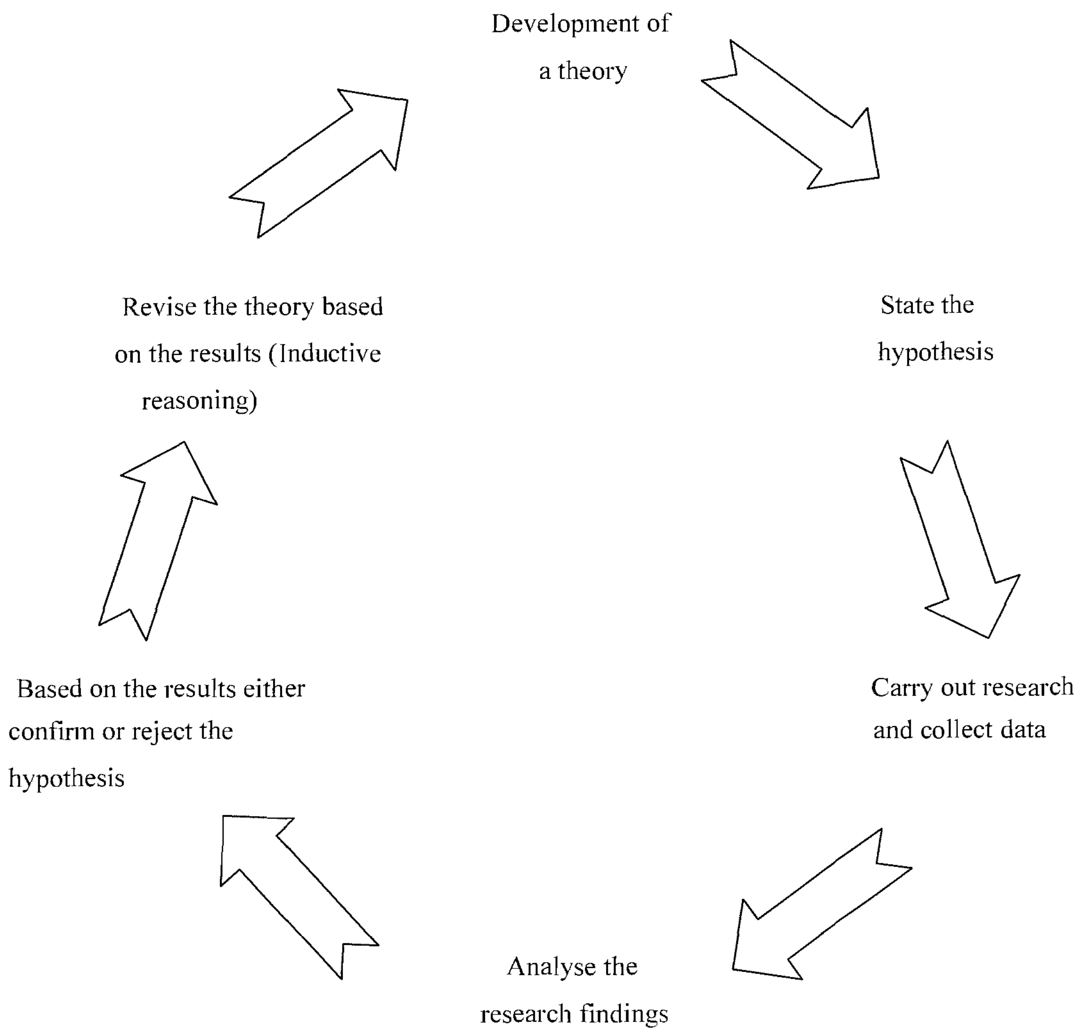
3.8.1 Hypothesis testing

Some research in the positivist paradigm involves hypothesis testing by which a researcher identifies a series of testable 'mini-theories' or hypothesis, based on their specific predictions derived from the general assumptions of a broad theory. This process is known as the 'hypothetico-deductive method' (Popper, 1959) and utilises the process of deductive reasoning. After defining the hypothesis to be tested the next stage of the process is to test the hypothesis by collecting data and analysing them. The process of deductive reasoning is shown below in Figure 3.1.

Deductive reasoning was used in the study reported in Chapter 4 which is broadly based on the depression models of grief (Stroebe and Stroebe, 1994) and the stress theory of bereavement, particularly the transactional social cognitive model of stress and coping developed by Lazarus and Folkman (1984). This model assumes bereavement is a stressor, which can impact on the health of the bereaved person. However, rather than taking a straightforward stimulus-response approach, it also takes into consideration psychological factors in the appraisal and response to stress.

Traditionally scientific notation requires the hypothesis to be written in the form of a negative statement termed the null hypothesis, worded in such a way that it states that no significant relationship exists between the variables. An example of the null hypothesis is X (IV) does not effect Y (DV). The positive version of the null hypothesis is the 'alternative hypothesis'. An example of the alternative hypothesis is X (IV) does affect Y (DV). When research is aimed at testing an hypothesis, the researcher attempts to demonstrate sufficient evidence to reject the null hypothesis and accept the alternative hypothesis.

Figure 3.1 **The process of hypothetico-deductive reasoning**



Rejecting the null hypothesis and accepting the alternative hypothesis acts to further strengthen the theory from which the hypothesis was derived. Conversely accepting the null hypothesis weakens the theory. However, theories do not equate with 'truth' or proof because theories can always be rejected at some point in the future based on further research. Statistical methods are used to judge the null hypothesis.

3.8.2 Statistical methodology

Statistical methods deal with populations and samples from populations and are concerned with the application of probability theory to quantitative data. In my analysis statistical procedures were used in the studies described in chapters 4 and 5.

3.8.3 Assessing the quality of quantitative research

The quality of quantitative research is judged in terms of scientific rigour, namely validity, reliability, and the generalisability of the findings. These will be described below and the assessment tools used each study discussed in the relevant chapters.

3.8.4 Validity

A valid instrument should accurately reflect all the domain and dimensions of the concept being measured. ***Face validity*** exists when an instrument is judged by the researcher to measure the concept that it is designed to measure. ***Content validity*** is more systematic than face validity and refers to the degree to which the content of the items comprising the instrument covers all the domains of the concept it is supposed to measure. It is evaluated by having experts or judges rate the items' content to their corresponding domain. ***Criterion validity*** is the correspondence between a measure and a criterion that is another 'gold standard' instrument measuring the same concept, which is administered at the same or different points in time. This type of validity is assessed by calculating a correlation coefficient or by conducting sensitivity and specificity analyses. *Construct validity* is the extent to which a measurement is related to other variables in a way that is consistent with theoretically derived predictions. In other words the extent to which the instrument tests the hypothesis of what it is measuring (Bowling, 2000).

3.8.5 Reliability

Reliability is the dependability of measurement and relates to the consistency and reproducibility of an instrument or measure. *Internal consistency* is the degree to which items in the instrument are interrelated and able to measure a single concept or dimension with minimal error. *Test-retest* measures reliability over time using. This measures the degree to which the same individual using the instrument reproduces similar scores when measured at different occasions (the stability of the test*).* *Inter-rater reliability* tests the agreement between two or more raters / observers using the same measure on the same or similar groups. Specific issues of reliability relating to the studies are outlined in the relevant chapters.

3.8.6 Generalisability

One of the aims of quantitative research is for the researcher to be able to generalise their findings to other situations beyond the confines of the study. The term generalisability is not generally applied to qualitative research; rather the term transferability is used. This is described later. It was intended that the findings of the study of bereaved people described in chapter 4 would be generalisable to a wider bereaved population, beyond the specific sample studied. Similarly the findings of the postal survey of DNs, described in chapter 5, was designed to be generalisable to the wider DN population in the UK.

3.8.7 Bias, error and confounding variables

One of the main threats to reliability and validity is bias and error. Sackett (1979) reported 35 different types of study bias. However, it is generally applied to one of the following situations: the researcher's inclination towards a particular position or conclusion which prejudices the study in some way; in statistical sampling it refers to a non representative sampling of the population being made, thereby negating the value of any generalisations; a systematic factor in a study that introduces error.

A confounding variable is any factor not controlled for (an extraneous factor) which distorts the results by being associated with the DV and the IV. One example applicable to this doctoral work would be the association between depression and older age. Any comparison of bereaved and non-bereaved people must control for the impact of age because if all the bereaved people (bereavement being the IV) in the study were older people compared to a younger non-bereaved people, then the finding of increased rates of depression (DV) in the bereaved sample may simply be confounded by age (confounding variable). Potential bias and confounding variables pertinent to the first two studies will be discussed later in this chapter when the studies are described.

3.9 Qualitative research

The conceptual framework of qualitative research has developed mainly from sociological and anthropological research with an aim to describe, understand and explain social phenomena. There are numerous methodologies within the qualitative paradigm and with such diversity of thought there has been much debate about what constitutes the central tenets of qualitative research. One definition suggests the purpose of qualitative research is to:

> *'study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meaning people bring to them'* (Denzin and Lincoln, 2000, page 3)

My work described in Chapter 6 was informed by the work of Guba and Lincoln (1989), Guba (1990), Denzin and Lincoln (2000) and Lincoln and Guba (2000). Constructivist-interpretivist (qualitative) research has an epistemological position that advocates gaining knowledge through the understanding of social action, meaning and behaviour. It assumes that the researcher not only has influence upon the findings but is part of the research process and described as a 'research tool' that interacts with the participants to 'construct' the findings. The belief system that social events and reality are 'constructed' rather than existing in reality is termed constructivism.

Denzin and Lincoln (2000) suggest the researcher should be thought of as a methodological *bricoleur* or 'jack of all trades' who is able to utilise various research tools and methods in obtaining and interpreting the data and the nature of the phenomena under observation. One of the most frequently used methods is the interview, particularly the semi-structured or unstructured interview. Other methods include: observations (participant and non-participant), analysis of written documents, and analysis of audiovisual material (e.g. photography, films, art work etc).

Qualitative research does not use the hypothetico-deductive methods employed by some positivist research, rather it uses inductive reasoning to generate explanations and theories based on the findings. The process (stages) of inductive reasoning is shown below in Figure 3.2.

Figure 3.2 Inductive reasoning

5	↑	Researcher develops a theory or compares patterns with other theories
4		Researcher looks for patterns (formulation of theories)
3		Researcher forms categories
2		Researcher asks questions
1		Researcher gathers information

(Based on Creswell, 1996; page 96)

Some qualitative methodologies can be complementary to quantitative work, through the development of theories using inductive reasoning which can be tested using quantitative methodologies (deductive reasoning) in a hypothetico-deductive cycle (see Figure 1). This is particularly relevant in grounded theory (Strauss and Corbin, 1990).

3.9.1 Judging the quality of qualitative research

Applying the rules of quality used in quantitative research to the constructivist-interpretivist paradigm raises particular problems due to fundamental differences in their ontological and epistemological perspectives. This has raised debate amongst qualitative researchers about the appropriateness of the use of applying such concepts as rigour (Koch and Harrington, 1998), validity (Morse, 1999; Angen, 2000, Whittemore et al 2001, Sparkes 2001) and reliability (Morse, 1999).

The principle aim of qualitative research is to describe, understand and explain social phenomena. The focus is frequently on specific social actors, social groups or particular phenomena and the results are not aimed at generalisation to a wider population per se. However, that is not to say that the results could never be transferred to another similar situation, as the results of qualitative research can be applied to other groups. Implicit in the constructivist-interpretivist ontological position is the concept of multiple socially constructed realities, each in a constant flux through the process of social interactions. In that sense absolute measures of reliability through comparisons of repeated interviews to participants would be meaningless, because at each interview there would be changes in the social interaction and many ideas could be revised and modified in light of experience and the analyses and interpretation of meaning changed to reflect this. However, it is argued that interviews tap into the constructed reality that exists in the mind of the interviewee, which provides a meaningful estimation of their perspective. It is this 'essence' or approximation of their reality that the interview aims to capture from the qualitative interviews and to interpret in the analysis.

There are a number of views about how qualitative research should be judged (Cutcliffe and McKenna, 1999, Sparkes, 2001). Hammersley summarises three distinct perspectives on how the quality of qualitative research should be judged:

- Qualitative research should be judged according to the same criteria as quantitative research.
- It is impossible, in a meaningful way, for any criteria to be used to judge qualitative research.
- Qualitative research should be judged according to criteria developed for qualitative research.

Cutcliffe and McKenna (1999) suggest a fourth perspective developed from triangulation as a method of establishing the credibility of qualitative research. These authors propose that qualitative research could be evaluated by carrying out a deductive study to test the credibility of the induced theoretical findings in the qualitative study. I agree with Hammersley's third perspective that it is appropriate to judge qualitative research according to criteria developed for qualitative research. From that perspective I chose to use Guba and Lincoln's (1989) four methodological criteria of trustworthiness namely: dependability, credibility, transferability, and confirmability, which were developed to establish the methodological safeguards of the study.

3.9.2 Dependability

Dependability relates to the concept of consistency and accuracy of the data and results. In the positivist tradition the related concept would be termed reliability, which is a precondition for validity. However, within the constructivist-interpretive framework a lack of stability in the findings can also be attributed to a number of sources including errors, but also reality shifts, and better insights (Erlandson et al, 1993). Erlandson suggests that the issue in dependability is not invariance but rather trackable variance which is required to explain the changes. It is therefore the responsibility of the researcher to show explicitly in the form of an audit trail how decisions were made and the results derived. The reader should be able to evaluate the adequacy of the researcher's analysis, from the elaborate descriptions outlined in the write up.

3.9.3 Credibility

Credibility has been compared with the positivist concept of internal validity. It is concerned with the accuracy of the match between the researcher's interpretation of the data and the constructed realities that exist in the minds of the participants. In other words does the researcher's interpretation of the data ring true for the participants? Credible research should provide depth of meaning and richness of understanding.

3.9.4 Transferability

Transferability has been compared with the concept of generalisability, although there are distinct differences. From the constructivist-interpretive perspective there can be no true generalisation of research findings because each is interpreted from within that particular context. Within qualitative research, transferability may occur across contexts when there are similar characteristics in those contexts. The key difference between the positivist concept of generalisability and the qualitative concept of transferability is that in the former, the onus is on the primary researcher to ensure that the results presented are generalisable to other areas, while in qualitative research the onus is on others (the readers of the research) to interpret and apply the findings to their own particular research context. To facilitate this potential transferability, it is therefore the obligation of the researcher to provide sufficient detail and description of the research findings to enable this to occur. Such a rich account has often been termed 'thick description', a term coined by the anthropologist Geertz (1973) to enable the reader to interpret the findings, make judgements, and facilitate understanding.

3.9.5 Confirmability

Confirmability has been compared to the positivist concept of objectivity. That is to say the findings have to be the product of the inquiry and not the biases of the researcher.

Within qualitative research the researcher is conceived as part of the research process (the research tool). Therefore there is an inherent risk of qualitative research being dismissed as being the views of the researcher unless evidence can be provided to demonstrate how the researcher came to each logical decision in their interpretation and construction of the findings. The evidence for confirmability is derived from the audit trail.

In addition to the criteria of trustworthiness Guba and Lincoln (1989) have argued for five additional criteria which they term authenticity. The principles of authenticity are based on an acknowledgement of the multiple constructed realities of the participants. It is suggested that these multiple realities must be given status in the lives of those individuals, in their particular context and in the report of the research. The five criteria of authenticity are: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba and Lincoln, 1989; Erlandson et al, 1993).

3.9.6 Authenticity

Fairness: This concept proposes that the researcher should demonstrate fairness to all participants during the research process and enable openness about the research should any vulnerable participant feel that they have been treated unfairly.

Ontological authenticity: This suggests a process by which the participants have been helped through the research process to a better understanding of their social world and human condition.

Educative authenticity: suggests that through the research process there is an expansion of participants' understanding and appreciation of their area. The research process is educational to the participant as well as the researcher.

Catalytic authenticity: represents the way in which the research process has facilitated decision making by the participants who now have a greater potential for action.

Tactical authenticity: refers to the way the research should empower the participants to act.

3.10 Ethical issues in bereavement research

Bereaved people are a vulnerable group and it is therefore important that research is carried out within a strict ethical framework. Beauchamp & Childress (1989) outline four principles of biomedical ethics, namely respect for autonomy, nonmaleficence, beneficence, and justice. The first three principles were pertinent to my doctoral research and will be outlined below.

3.10.1 The principle of autonomy

Autonomy is derived from the Greek autos (self) and nomos (rule, governance or law) and applied to my research implies that a person should be able to make a choice about participation. In the first study which involved assessments of bereaved people I obtained Local Research Ethics Committee approval to carry out the study. This is described in chapter 4. Each bereaved person was provided with an information sheet describing the study, a consent form and ample opportunity to speak to myself or Professor Kendrick before deciding to participate. The consent form ensured each participant provided written informed consent. It was made clear to each person that they were free to withdraw from the study at any stage. Similarly in my interviews with DNs (Chapter 6) I obtained written informed consent to carry out the interview. Following the audiotaped interview all tapes and transcripts were anonymised and any personal information removed so that individuals could not be identified. When carrying out my survey of DNs (Chapter 5) I used the DN manager to distribute the survey anonymously so that the identity of all respondents remained unknown to me. All DNs were free to decline participation.

3.10.2 The principle of nonmaleficence

The principle of nonmaleficence is associated with the maxim "*Primum non nocere*" Above all do no harm (Beauchamp and Childress, 1989, p 120). It was not my intention to cause distress to any participant and therefore when carrying out the assessments with bereaved people I was sensitive to their needs to talk about the deceased person. Each participant was also told at the start of the assessment interview that any questions that made them feel uncomfortable or embarrassed should be left out. As a nurse I had developed empathic listening skills and I used these during the interview. Participants were asked if they wanted a break if they appeared upset. I was aware that discussing their loss may bring back memories and make them feel sad after I had left. Therefore at the end of each visit I tried to end the interview with a general chat about everyday events and before leaving I provided them with my contact number and a leaflet about bereavement (Royal College of Psychiatrists, 1998) which provided information about grief, bereavement and services available.

In my audiotaped interviews with DNs the situation was different. I treated them as health care professionals and aimed to explore their role in bereavement support although the topic of personal loss did arise. At the end of the interview I provided my contact details and offered the bereavement leaflet. In addition to possible harm to the participant, one should also consider the potential distress to the researcher. Everyone has painful memories and repeated interviews with bereaved people can leave the interviewer distressed which may have a negative impact on mood. The possibility of this was discussed with both supervisors and I was provided with the opportunity to discuss any of these issues during my regular supervision session.

3.10.3 The principle of beneficence

The principle of beneficence implies that some form of benefit should be gained through the action of research or treatment. In a wider sense the aims of the research were to benefit all bereaved people through its development of further knowledge of that area. While no specific benefits were planned for the bereaved person it was hoped that through their participation in the research process they would feel that they had made a valuable contribution to bereavement research which would help other people. In addition the act of discussing their own bereavement may help some people.

Parkes (1995) suggested guidelines for conducting ethical bereavement research and these were implemented at each stage throughout my research. Areas considered were: gaining access to bereaved people, informed consent, preventing possible harm to respondents, there being no personal gain to researchers, not putting pressure on people to participate, training interviewers in the support of bereaved people, supervision of interviews, confidentiality, minimising stress during the interview, and rigorous methodology.

3.11 Mixing qualitative and quantitative research

Qualitative and quantitative research methodologies are frequently dichotomised as fundamentally incompatible paradigms derived from mutually exclusive ontological and epistemological positions. Whilst accepting fundamental differences in methodologies derived from different paradigms, one should not accept that researchers must be confined to carry out research exclusively within any particular paradigm and in my doctoral work I have used a mixed methods approach. Chapter 4 and 5 use a positivist methodology in the form of assessments of bereaved people and a postal survey of District Nurses, respectively. However, in Chapter 6 the methodology is within the constructivist-interpretive paradigm, with a semi-structured qualitative interview as the research method (Smith, 1995; Payne, 1999).

My ontological perspective is somewhat mixed. As a nurse and health researcher I utilise both a quantitative and qualitative evidence base to inform my practice. I utilise research that has used quantitative methods such as randomised controlled trials and meta-analysis to identify the best treatments for patients. However, I believe the complexity of human interaction cannot be easily explained in purely quantitative terms and qualitative research is often valuable in gaining a deeper understanding of a particular area.
For example Bradley et al (1999) and Wiles (1998) used mixed methodologies to examine the impact of a lifestyle intervention on cardiovascular risk. Based on in-depth qualitative interviews with 25 people recovering from heart attacks, the results indicated that the provision of information by health professionals about recovery (based on epidemiological data) was not sufficient to make a lasting impact on lifestyle over time (Wiles, 1998). The results from the qualitative methods were essential to understanding the failings of health promotion in this patient group, and informed alternative approaches for the delivery of health information.

Knowledge can be gained from diverse research methodologies and I propose that research should utilise the appropriate methodology to answer the questions posed. Sackett & Wennberg (1997) attacked the wasted effort being invested into squabbling over which was the best research method and suggested that researchers should choose the best research design for each question. They state

> '*Our thesis is short: the question being asked determines the appropriate research architecture, strategy, and tactics to be used-not tradition, authority, experts, paradigms, or schools of thought*"
> (Sackett and Wennberg, 1997: page 1630).

My choice of a mixed methodology constitutes between-method triangulation. Each method enquires about a different facet of bereavement support, which adds to the total knowledge base. Each is treated with equal importance in the overall study rather than one methodological perspective having a dominant epistemological position.

Chapter 4 Interviews with and assessments of bereaved people

4.1 Introduction

The literature review of bereavement related mental health problems in Chapter 2 reported that little was known of the range of mental health problems in bereaved people in the UK outside selected groups in specialised settings. Bereaved people may be reluctant to seek help due to fear of stigma, and it is likely that many problems go unreported and undetected. The aim of this study was to explore three specific questions. Its primary aim was to measure mental and physical health problems in a broader primary care population of widowed people (including those who had lost a partner) and compare it to a matched non-bereaved control group. This would ascertain whether bereaved people had higher levels of mental health problems and or other vulnerabilities that the primary care services could target support. Secondly, it was hoped that it would identify risk factors for a poor outcome among bereaved people. It aimed to explore the relationship between primary care provided and the extent of mental and physical health problems in the 13 months following bereavement. However, I was aware that one must be cautious when evaluating associations between support and mental health outcome, because associations do not imply any causal effect. Extra support may be associated with poor mental health outcome because the extra support is provided to those experiencing difficulties, who require greater support. Alternatively extra support may be associated with a better outcome because the support enables the bereaved person to cope with their loss, which in turn reduces their risk of developing mental health problems.

The literature review of primary care support for bereaved people, discussed in chapter 2, identified that GPs were divided over what type of bereavement support, if any, to offer to bereaved people and whether it should be proactive or reactive. There was also limited research evidence to assess how useful bereaved people had found the support provided by the primary care team. In light of the relative lack of research into bereavement from a primary care perspective, the third question that the study aimed to address was the type of support provided by the primary care team from the perspective of both the bereaved person and the GP. This would inform the debate about the need for a bereavement protocol in primary care and also measure the perceived value of any support provided, from the service user's perspective. Taken together with an assessment of the mental and physical health experienced by bereaved people, it would also be possible to explore the relationship between primary care support and mental health outcome.

The study started as a prospective case control study, but was eventually modified to take recruitment problems into consideration. It is reported as a descriptive case series but uses the same principles and measurements originally chosen. Although the results were limited due to poor recruitment, the research process is described in detail and provides a number of suggestions for future research in this area.

4.2 Methods

This study used a prospective case control design with the purpose of measuring the mental health status of a representative sample of bereaved spouses or partners. In a cross-sectional study cause and effect cannot be determined, therefore only associations were examined.

4.3 Objectives

The study had three main objectives:

- (i) to describe the extent of psychiatric morbidity (e.g. depression, anxiety) in a UK Primary Care (PC) population at three and 13 months post bereavement compared to a non-bereaved sample from the same practices.
- (ii) to describe current primary care practice in the assessment, care and support of bereaved patients and to explore the relationship between primary care support, social support and mental health outcome.
- (iii) to measure patients' ratings of helpfulness of primary care support provided within the first three months.

4.4 Primary null hypothesis:

There are no differences in the levels of depression and anxiety between spousal (or partner) bereaved people and non-bereaved married or partnered people of similar age from the same general practice

4.5 The secondary null hypothesis:

The levels of depression and anxiety in spousal (or partner) bereaved people remain the same in the first 13 months following the death.

4.6 Instruments used in the assessment

4.6.1 The primary outcome measure

The primary outcome measure was the point prevalence rates of depression and anxiety. The assessment tool chosen for that was the Clinical Interview Schedule Revised (CIS-R) (Lewis, 1992) (see appendix. 1). The CIS-R was selected because it had been used as the main assessment tool in the British office of population census and statistics (OPCS) psychiatric morbidity survey (Meltzer et al, 1994). This provided an estimate of psychiatric morbidity in a UK primary care population for those aged 18 to 65 years. Its use in a primary care population made it a useful assessment tool because the results could be compared to the findings of a larger population as reported in the psychiatric morbidity survey. The revised CIS-R is a structured psychiatric interview designed for use by lay interviewers to assess symptoms of depression and anxiety, but not psychosis. The CIS-R was developed and validated using a British primary care population. Using the CIS-R removes the need for clinical judgements about a diagnosis; it is briefer than other standardised interviews and allows both dimensional and categorical descriptions of mental illness.

There are two versions of the CIS-R, the paper version and the computer version. At the time of the study, cost prohibited the purchase of a laptop and so the paper version was used. There are 14 separate sections covering somatic symptoms, fatigue, concentration and forgetfulness, sleep problems, irritability, worry about physical health, depression, depressive ideas, worry, anxiety, phobias, panic, compulsions and obsessions and there are a further two sections covering depression. Each section starts with mandatory questions that ask about problems experienced in the past seven days, which are used to assess the evidence of the condition. At the end of the mandatory questions there is a decision algorithm that directs the interviewer to continue with the diagnosis or to 'cut-off' and move onto the next section. This process can speed up the interview, if the person has few mental health problems. However, if the person responds positively to the mandatory questions then further specified questions are asked to ascertain the nature and severity of the symptom. A dimensional view of psychiatric illness is taken such that each participant is given an overall score between 0 and 57. This indicates overall psychological distress in the preceding seven days. The recommended threshold is 12 and those scoring 12 or more are regarded as "cases" of common mental disorder. If the assessment is carried out with physically ill populations, the fatigue item is omitted with the case definition reduced to a score of 11. A similar allowance can be made for the item about worry about physical health. If both items are omitted, the case definition value is reduced to 10.

The CIS-R has been shown to have good inter-item (Cronbach's alpha 0.82) and test-retest reliability (correlation 0.91) (Lewis et al, 1992). A kappa of 0.70 (95% CI 0.51, 0.88), was obtained for inter-rater reliability between a psychiatrist and a trained lay interviewer. Furthermore there was no evidence of bias between the two interviewers and the interview total score has been shown to be reliable compared to psychiatrists' impressions of the severity of the person's common mental disorder (correlation 0.77) (Lewis et al, 1992). Algorithms have also been developed to enable allocation of diagnoses of specific psychiatric illness according to criteria in the 10th International Classification of Diseases (WHO, 1992).

Disadvantages of the CIS-R

The study on which the CIS-R was developed was based on a UK Primary Care population in a deprived inner city area but the response rate was only 10%, and included a relatively large proportion of participants (7%) who had previously seen a psychiatrist (Lewis et al. 1992). In addition the CIS-R was validated on a population aged between 18 and 65 years. To clarify if the CIS-R would be applicable to an older population, the author of the questionnaire (Professor Glyn Lewis) was contacted. It was his opinion that it could be used on people older and would still be valid up to 75 years old.

4.6.2 Secondary outcome measures

Four validated questionnaires were selected for administration to the participants: the SF36, the six-item version of the Social Support Questionnaire (SSQ), the Inventory of Traumatic Grief (ITG), and the Grief Experience Questionnaire (GEQ). In addition a form was designed to record demographic details about each person, and two questionnaires were designed to assess bereaved peoples' ratings of the 'helpfulness' of support provided by the primary care team in the three months following the death, and a questionnaire for the GP of the bereaved person.

The SF 36 generic measurement of health status

The 36-item short form of the Medical Outcome Study Questionnaire (SF-36) (Ware, 1990, Ware & Sherbourne, 1992) is a well validated generic measurement of health status which was chosen as being suitable for administration to all participants. It is relatively easy to complete and takes approximately five to ten minutes (See appendix 2).

The SF36 was developed by the RAND Corporation for their Health Insurance Experiment (1974 – 1982) and later their Medical Outcomes Survey, a large American multi-centre primary care study of health status. It has also been adapted for British use by minor alterations to the wording of some items. There are a number of versions of this questionnaire (e.g. SF-20 & SF-36). The SF-36 is so named as it contains 36 items; it has eight dimensions and a question asking about perceived health changes over the past year. The questions cover: social functioning, bodily pain, physical functioning, role limitations due to poor physical or mental health, mental health, energy/vitality, and general health perceptions). For each dimension item scores are coded, summed and transformed linearly to a scale ranging from 0 (poor health) to 100 (good health).

In one UK primary care population inter-item correlation (Cronbach's alpha coeficients) ranged from 0.73 to 0.96 (Jenkinson, et al, 1993), although in patient groups with psychiatric and complicated medical diseases the alpha coefficient has been as low as 0.65 (McHorney, et al 1994), which is below the recommended 0.70 when comparing groups (Nunnally, 1978).

Each scale on the SF-36 has undergone criterion validation on the full length MOS parent version (Ware & Sherbourne, 1992) and in the UK using data from the Oxford Healthy Life Survey (Jenkinson, et al 1994). The SF36 also has good construct validity as indicated by the use of psychometric and clinical criteria. The psychometric criteria were used to assess the extent to which each of the eight dimensions was indicators of the two underlying concepts of physical and mental health. To achieve this the validity of each scale was measured and compared to the 'most valid scale' for each of the two dimensions (mental or physical health) (McHorney, et al 1994). The clinical criteria were tested on four groups differing in mental or physical health status. Both psychometric and clinical tests provided support for construct validity (McHorney, et al 1994). Normative data have been provided for a British population (Jenkinson, et al 1993).

Social Support Questionnaire

The six-item abbreviation of the Social Support Questionnaire (SSQ) was chosen to measure all participant perception of the social support available (Sarason et al 1987) (see appendix 3). Social support can act as a buffer to stress and it was chosen to measure an association between social support and mental health. The SSQ was developed to measure the availability of social support and the satisfaction with that social support (Sarason et al, 1983). The original full SSQ is a 27 item questionnaire which provides an overall support score, based on the number of support people listed (the 'number' score) and an overall satisfaction score based on the mean of the 27 satisfaction scores. The correlation of each item with the total 'number' score (omitting the item) ranged from 0.51 to 0.70 with an alpha coefficient of internal reliability was 0.97. The inter-item correlation ranged from 0.21 to 0.74, with an alpha coefficient of 0.94. The test retest correlation coefficient was 0.90 for the overall number score and 0.83 for the satisfaction score (Sarason et al 1987).

Factor analysis on the two types of score reveals a strong first factor for each score which accounts for 82% of the variance in the 'numbers' score and 72% of the variance in the satisfaction score. Sarason argues that the two scores represent different dimensions of social support. The six-item abbreviated SSQ consists of items loaded highly on the 'number' and satisfaction scores, namely items 9,17,19,20,23, and 25 of the full version. The alpha coefficient measure of internal consistency was 0.9 for the 'numbers' and 0.93 for the satisfaction scores. Correlation coefficient for the 27 item SSQ (omitting the common items) were 0.95 for the 'numbers' and 0.96 for the satisfaction scores.

Inventory of Traumatic Grief

Traumatic grief is an emerging concept which has been developed from attachment theory (Bowlby, 1980; Jacobs, 1999). It is considered a form of pathological grief in response to the death of someone. The inventory of traumatic grief (ITG) was based on and developed from the inventory of complicated grief (ICG) (Prigerson et al, 1995). The ICG is a 19 item questionnaire with a high internal consistency (Cronbach $\alpha = .94$). Test retest reliability was calculated as 0.80 and was based on 28 subjects who repeated the questionnaire six months later and were in a steady state of depression. Concurrent validity was good and based on associations with three other measurement scales: Beck's depression inventory (Beck, 1967) ($r = 0.67$, $P<0.001$), Grief Measurement Scale (Jacobs et al., 1989) ($r = 0.70$, $P<0.001$), and Texas Revised Inventory of grief (TRIG) (Faschingbauer et al, 1977, 1987) ($r = 0.87$, $P<0.001$). Respondents with ICG scores greater than 25 (20% of the sample) were found to have significantly more impairments in social, general, mental and physical health functioning and also worse body pain than those with scores of 25 or less. Therefore a cut off of 25 was identified as the criterion for complicated grief (Prigerson et al., 1995). The complicated grief criteria set used in the ICG was refined at a consensus meeting of experts (Prigerson et al, 1999) and the term 'traumatic' grief adopted. The ICG questionnaire was subsequently modified and renamed the ITG, which is a 34 item questionnaire (see appendix 4). All the original question in the ICG are used although there are some slight changes to the wording. The ITG is designed to produce a diagnostic criteria for traumatic grief and was found to be highly sensitive and specific in correctly classifying 93% of the predetermined "cases" (true positives) and 93% of the predetermined "noncases" (true negatives) of complicated grief (Prigerson et al., 1999). The ITG is designed to be a diagnostic tool and aims to produce a diagnosis classification in accordance with the American Psychiatric Association Diagnostic and Statistics Manual (DSM- IV). Because the ITG is a measure of bereavement anxiety it was administered to bereaved people only.

Grief Experience Inventory

The Grief Experience Inventory (GEI) (Saunders et al, 1985) consists of 135 statements associated with grief and bereavement (see appendix 5). Grief is viewed as a multidimensional measure of bereaved people's experiences of grief, and each statement is answered with a 'true' or 'false'. There are two main parts to the GEI, the three validity scales and the nine bereavement scales. The bereavement scales consist of: despair, anger/hostility, guilt, social isolation, loss of control, rumination, depersonalisation, somatisation, and death anxiety. The three validity scales are: denial, atypical response, and social desirability. In addition there are also six research scales: sleep disturbance, appetite, loss of vigour, physical symptoms, optimism/despair, and dependency, but these were not recommended. The raw score for each scale can be transformed into a T-score, which is a standard score with a mean of 50 and standard deviation of 10. The raw scores can be plotted on the GEI profile to show a graphical representation of the bereaved person's grief.

The reliability of the subscales has been assessed, yielding alpha coefficients of internal consistency which range from 0.52 (for the six-item guilt scale) to 0.81 (for the 20-item somatisation scale) (Sanders, et al 1985). Factor analysis reveals three factor scores. The first is termed a 'general grief indicator' which represents common experiences of grieving such as dysphoria, isolation and physical symptoms and accounts for 76.6% of the variance. The second is described as 'internal experiences of grief' and accounts for 15.5% of the variance. The third is a measure of 'denial as a coping mechanism for grief' and accounts for 10% of the common variance.

To assess the validity of the GEI, intercorrelations were made between the GEI scales and scales on the Minnesota Multiphasic Personality Inventory (MMPI). Many of the GEI scales appear to be unrelated to their corresponding MMPI scales, which Saunders proposes is evidence that the GEI scales are measuring behaviours which are similar to those assessed by the MMPI scales, but that the GEI scales tap aspects of bereavement not sampled by the MMPI (Saunders et al, 1985). This supports the theoretical foundation of the GEI scales. The validity of the GEI has also been tested through its ability to distinguish bereaved from non-bereaved people. A modified version, omitting five of the scales which referred to a specific death (e.g. despair, guilt, rumination, depersonalisation, optimism / despair) was administered to non-bereaved people and compared to the bereaved group. A t test between the two groups revealed a significant difference at $p = 0.001$ on all the scales (Saunders et al, 1985), suggesting that the GEI was measuring specific features related to bereavement (grief). In addition the GEI was able to distinguish between those who had lost different family members (parent, child, and spouse) with the loss of a child gaining the highest scores. When compared across the three groups using a univariate analysis of variance, nine out of eleven of the scales differed significantly (Saunders et al, 1985).

Demographic details of participants form

A form was designed to collect background information about each participant (see appendix 6). This form was developed through consultation with both supervisors and had face validity. It covered five key areas: (1) *Personal details* comprised 23 questions covering such areas as name, age, gender, religious worship, and contact with children.; (2) *Demographic details* comprised five questions regarding type of accommodation, academic achievement, and employment status; (3) *Heath information* comprised 11 questions about aspects of health before and after the bereavement including details of smoking, alcohol consumption, and prescribed medication; (4) *Financial information*, comprised two questions; (5) *Previous bereavement* comprised of one question about previous bereavement and details of who had died, the date of the death and impact the loss had using a Likert scale from 0 (no impact) to 4 (extremely upset).

Helpfulness of primary care support

A questionnaire was designed to measure bereaved people's views about bereavement support provided by the primary care team within the first three months following the death. This was administered to bereaved people only (see appendix 7). This form was developed through consultation with both supervisors and had face validity. The questionnaire comprised of 13 questions. Nine of the questions used a Likert scale to measure the bereaved person's satisfaction with aspects of primary care support ranging from 'no help at all' to 'extremely helpful'. Three questions provided the person with the opportunity to make written comments or suggestions for improvement in the services provided.

Questionnaire to GPs

A questionnaire was also designed to record demographic data about the GP who referred the bereaved person. It was designed to record details of the GP practice and to measure the GPs' views about bereavement support, and the support provided to the participating bereaved person within the first three months following the death. (see appendix 8). There were 17 questions covering five main sections: (1) Demographic details of the GP and practice; (2) the GPs interest in bereavement; (3) the GPs beliefs about what bereavement support should be provided; (4) general background information about what the general practices policies were in respect to bereavement; (5) specific questions about the support provided to the bereaved person participating in the study.

4.7 The population

4.7.1 Defining the bereaved sample

Defining the sample population allows a mutually exclusive category to be described and an inclusion and exclusion criteria to be developed. The sample population is defined as the sampling unit (Bowling, 2000). In this study I defined the sampling unit as bereaved people, aged between 50 and 75 years, who had lost a spouse or partner three months previously. The justification of the age limits is provided below.

4.7.2 Defining the non-bereaved sample

The non-bereaved sample was defined as non-bereaved people, aged between 50 to 75 years, from the same GP practice as one of the bereaved sample, who were married or living with a partner. Any person who had experienced the death of a significant other would also be excluded. The same GP practice was chosen to minimise bias due to health differences in the populations served by the practice.

4.7.3 Defining the term 'partner'

For the purpose of the study, a partner was defined as someone with a co-habiting relationship of at least 12 months. The term partner also allowed for same sex relationships to be included in the sample, which would otherwise be excluded if only spouses were used. Twelve months was a somewhat arbitrary figure, although it was reasoned that partners who had co-habited for at least 12 months would reflect a long-term relationship.

4.7.4 The age of the sample

Widowhood is relatively rare in those under 50 years old. Although the CIS-R was validated on a population aged between 18 and 65 years, it was considered by its developer that it could be used on people older and up to 75 years old (Glyn Lewis 1999, Personal communication). When measuring mental health problems, it is important to consider problems due to cognitive decline demonstrated in older populations, particularly in those over 75 years old (Hoffman et al, 1991), which might make the measurement of anxiety and depression much less reliable. Prevalence studies have consistently shown that the prevalence of dementia increases with age. A review of 12 European surveys found the prevalence of dementia at age 65 was 1% and at 75 years it was 5%. However, by the age of 80 it was 20% and around 33% in those over 90 years old (Hoffman et al, 1991). Based on the evidence, it was decided to focus on bereaved people aged 50 to 75 years, to exclude older people who had an increased likelihood of cognitive impairment.

4.7.5 The geographic location and selection of cases and controls,

For pragmatic reasons due to limited travel time, it was decided to use the local counties of Hampshire and Dorset to recruit participants.

4.7.6 The size of the sample population

The power calculation estimated that 65 bereaved and 65 non-bereaved people would be required to demonstrate a significant difference on the primary outcome measure (CIS-R) at the 5% significance level based on 80% power. This is described in detail below.

Statistical tests are sensitive to sample size. If the sample size of a study is too small then statistically significant differences may not be detected even when there actually is a difference. This would result in a failure to reject the null hypothesis when it is actually false (termed a type II error). For the purpose of this study, I required sufficient numbers of people in the samples to enable the statistical tests to be both statistically and clinically meaningful. The sample size of a study is determined by four quantities, namely the power, the alpha-level, the smallest meaningful difference, and the standard deviation of the variable (the variability) expected to be present in the data that you collect. There are three components to the power of a test, namely the true difference between the populations, the significance level chosen and the sample size (Bland, 1995).

The alpha-level (α) is the probability of rejecting the null hypothesis when it is actually true, which is termed the type I error. The alpha-level is usually set at 0.05 by convention, which implies a 5% probability of making the type I error.

The power of a study is the ability to reject the false null hypothesis when the alternative hypothesis is true. Power is defined as 1 - β (Beta), where β is the probability of making a type II error and usually ranges between 10 to 20%, making the standard levels of power between 80 to 90%.

Based on the results of a previous study of people with emotional problems (Mynors-Wallis et al, 1997), which reported a standard deviation (SD) of 10.9, it was considered that a difference of approximately half the reported SD, that is five points or greater on the CIS-R (the primary outcome measure) would be considered clinically significant. The power calculation was based on the standard equations used to calculate sample size (Kirkwood, 1988; Armitage and Berry, 1994) and used an independent parametric t test with a standard alpha significance level of 0.05 and power of 80% (see Figure 5.1). The standard deviation of the variable (the variability) is necessary for the calculation and this was obtained from a previous study using the CIS-R on a UK sample of primary care attendees at a South East London Health Centre (Lewis et al 1992). This was calculated to be 9.4.

An evaluation of the previous work using the CIS-R indicated that the data would probably be skewed to the right (Lewis et al, 1992 page 476) and therefore a parametric test would not be the appropriate method as this violated one of the parametric assumptions of the data being normally distributed. To adjust for this, it was decided that the Wilcoxon-Mann-Whitney non-parametric test (Siegel and Castellan, 1988) should have been used to estimate the difference between the control and bereaved groups. Because the non-parametric test is approximately 95% as powerful as the t-test it was easy to modify the t test calculation and make a correction to the final estimated numbers of participants. Siegel and Castellan (1988) suggest a correction can be calculated by dividing the estimated number by 0.95, which increases the numbers required to find a difference when using a non-parametric test. Therefore the estimated 112 subjects when divided by 0.95 equalled 118, or 59 subjects per group. However, it was decided to compensate for an attrition rate of approximately 10%. Therefore the total number of participants required was 130, based on 59 + (59 x 10%) = 59 + 5.9 (rounded to 65) (See Figure 4.1)

Figure 4.1 Sample size needed for the study based on the t test

$$N = 2 \times \frac{(V + U)^2 \ SD^2}{Delta^2}$$

V = Percentage point of the normal distribution corresponding to the (two sided) significance level, e.g. if significance level = 5%, V = 1.96

U = One-sided percentage point of the normal distribution corresponding to thepower, e.g. if power = 80%, U = 0.84

SD = Standard deviation. The SD for both groups is assumed to be equal. So rather than use the equation $SD_1^2 + SD_2^2$ the equation is doubled (with the 2 in front).
In this case SD = 9.4.

Delta = The difference between the means to be detected (five points).

$$N = 2 \times \frac{(1.96 + 0.84)^2 \ 9.4^2}{5^2}$$

$$N = 2 \times \frac{7.84 \text{ X } 88.36}{25}$$

$$N = 2 \times \frac{692.7425}{25} = 2 \times 27.7097$$

N = 55.4 (rounded up to 56)

4.8 Interviews and assessments

It was important that any measurement of mental health problems was carried out at a time that had minimum intrusion on the grief of the person, but captured a baseline measurement of any post bereavement mental health problems. The time of three months post bereavement was chosen as it was sufficiently close to the time of death for the person to recall particular support from the primary care team, yet at a time that allowed appropriate time for grieving to have commenced. Immediately following the death some people may experience a sense of shock, numbness and disbelief (Bowlby 1980; Parkes 1972). There are also other considerations such as the funeral. Charlton and Dolman, (1995) suggest that the primary care team should aim to give bereavement support in the first three months following bereavement. The study would enable me to evaluate their assumption that three months was an optimal time for assessment and potential intervention, by assessing the range of mental health problems in bereaved people close to the death. It was decided to repeat the measure at 13 months post bereavement. Thirteen months is an accepted time in bereavement research as this avoids the anniversary of the death, which can results in a period of increased 'grief' at the memory of the loss, that could have inflated and biased the post bereavement measurement of depression and anxiety. In addition, although a slightly arbitrary time scale, one year following the death of a spouse or partner is often seen as the length of time that a GP would have expected the bereaved person to return to a 'normal' state of life.

4.9 Data collection

The method of data collection was a face-to-face interview, administered to participants either in their homes or at their GP surgery depending on their choice. A face to face interview was chosen as the most appropriate method of assessment for bereaved people, as the CIS-R questionnaire is designed for face-to-face interviews. Also, being present with the bereaved person would allow me to conduct the interview in a sensitive manner and to be mindful of any emotional difficulties as they appeared in the interview. Having a person present provides support and allows the interviewer to read the person's body language.

4.10 Potential bias and error

Two main potential sources of bias and error were identified in this study and attempts made to reduce them. *Non-response* bias is due to the differences in characteristics between responders and non-responders. This may have been a potential source of bias as some potential participants were sent letters by their GPs and I was only aware of those who responded. Due to the overall small numbers who were recruited, this was not a major concern. *Interview bias* occurs when the interviewer biases the respondents to answer in a particular way. Using objective measures reduces this although my presence may have influenced the way certain responses were made.

4.11 Analysis

All the data were coded, then entered and analysed using into statistical software package SPSS Version 10 for Windows (SPSS. Inc., 1999). The data were coded and input according to the type of data accepted by SPSS, namely nominal, ordinal or scale data (sometimes referred to as interval/ratio data). Some data were also input as free text. The questionnaires completed by the participants are shown in Table 4.1.

CIS-R: The CIS-R total scores were computed by summing the scores for each individual section. The total scores for the CIS-R were input as interval data and used in the analysis. Where possible the data was input for both the first and second interview.

SF-36: The scores for the SF 36 were calculated using the system outlined in the U.K. SF-36 analysis and interpretation manual (Jenkinson et al, 1996). The manual guides the user in the creation of the eight dimensions of the SF-36, namely physical functioning, role-physical, role-mental, social functioning, mental health, energy, pain, and health perception. A ninth category measures change in health in the previous year and is not used to score any of the health dimension. Where appropriate the data were input at the first and second interview.

Grief Experience Inventory (GEI): The scores for the GEI were calculated using the system outlined in the manual for the GEI (Saunders, et al 1985). The manual provides instruction about how to calculate the three validity scales (denial, atypical response, and social desirability) and the nine bereavement scales (despair, anger/hostility, guilt, social isolation, loss of control, rumination, depersonalisation, somatisation, and death anxiety) from the 135 questions. None of the questionnaire research scales were used. To score each scale, a cardboard scoring grid for each of the scales was laid precisely over the questionnaire and lined up to the reveal the questions to be summed for that particular scale. The questions that are summed contribute one point to the total score for each scale. Although the questionnaire consists of true and false answers, these vary as to whether responses score a point or not. The total scores for each of the scales was input.

Inventory of Traumatic Grief (ITG): The ITG was coded according to the criteria laid down in the questionnaire and input into SPSS as categorical (binary) data as either fulfilling the criteria for traumatic grief: (Yes) or not (No).

Six Item Social Support Questionnaire (SSQ): The SSQ total scores were computed by summing the scores for each individual question. The total scores were then input as interval data. The SSQ also allows people to list up to nine people who they can count on as a support resource for each of the questions.

Demographic data: The majority of the demographic data from the participants was categorical in nature e.g. gender, relationship of the bereaved person to the deceased, ethnic group etc. However, age was coded as interval data and cause of death in note form as a string variable.

Helpfulness of primary care support: The data from the helpfulness' of primary care support questionnaire was either categorical (or nominal) data or ordinal data. Nominal data such as whether GP's visited (Yes or No), were coded numerically (1= Yes and 2 = No) and input. When the data were ordinal as in the ratings of helpfulness for each primary care action, the rating was allocated a numerical value to reflect the order of the scale (e.g. no help at all = 1, a little help = 2, helpful = 3, very helpful = 4, extremely helpful = 5). However, ordinal data does not represent an equal difference between the statements on the scale (as with interval / ratio data), it only shows the order.

Questionnaire to GPs: As with the helpfulness questionnaire, the data from the GP questionnaire were mainly categorical (or nominal) data or ordinal data and coded in a similar way. However, GP age was input as ratio/interval data.

4.12 Recruitment of bereaved people

There are a number of ways in which one can approach bereaved people, including gaining the list of deaths from the births/ deaths registrar and contacting people directly, approaching a hospital and contacting the spouses and partners of those who had died, and checking the deaths section of a local newspaper. However, after careful consideration these were not viewed as appropriate options. Because the focus of the study was to assess a primary care population it was decided to contact and recruit bereaved people via GP practices. The main advantages were that the sample would be derived from the population of interest, GP records could identify a large number of people, and bereaved people may be more willing to assist in research perceived as being helpful to their GP. Also, as the study also wanted to describe the impact of primary care support, it was important to try and get the GPs' interest and cooperation. Other advantages were that it avoided 'cold contact' with bereaved people, avoided the bias of only contacting the spouses of people who had died in hospital, and demonstrated respect to the bereaved person's doctor which I hoped would gain their support with the research. To achieve the required number of bereaved people (65) it was estimated that approximately 25 general practices would need to be recruited to the project, with two or three bereaved people coming from each practice. By spreading the recruitment across a large number of practices, it was hoped to reduce the 'burden' on any one practice and encourage GPs to participate.

However, there are potential disadvantages to recruiting via GPs, particularly the risk of bias. GPs willing to help may be self selected due to their interest in bereavement. There is also the potential for GPs to select bereaved people on the grounds of particular characteristics. They may select those who are frequent attendees to the practice due to emotional problems. This may occur for example if the GP either believes that participating in the study will help them or that participating might reduce patient visits to their practice. It was hoped that the potential for bias could be reduced by explaining the importance of the study to each GP. In addition each GP were also going to record anonymous demographic details of patients who were not selected on clinical grounds or for other reasons, so that they could be compared with patients who were selected and who subsequently participated. Another difficulty was the potential of finding that different practices had different proportions of people with mental health problems. For example there is evidence that practices in a less affluent area may have a large proportion of people with depression (Ostler et al, 2001). To control for that it was decided that a married or partnered practice-matched control group would provide both a comparison group against which to compare the bereaved group and a way of controlling for the practice effect. It was decided that for each bereaved person recruited for interview, a married or partnered control person of a similar age and sex would be selected from the practice and interviewed.

4.13 Recruitment of non-bereaved people

Non bereaved people would only be interviewed once. As the study aimed to compare the mental health of bereaved people with this non-bereaved sample, the timing of the interview was unimportant. It was acknowledged that the control group may also be exposed to events that could precipitate changes in mental health or there may be a natural fluctuation over time. However, this method can be justified because the aim was to sample a non-bereaved population cross-sectionally and I was interested in the differences between the two sample populations, which were matched for GP practice and overall age-group. Although there would be individual fluctuations in mental health over time it was hoped that the control group would be relatively stable.

4.14 Matching the case and control sample,

Because of the nature of the study it was not possible to have randomised groups, therefore matching was used to control for known confounding variables.
For example being a member of a lower socio-economic group might be associated both with a greater risk of bereavement (the independent variable) and greater mental health problems (the dependent variable). If this were the case it would be difficult to disentangle the effects of bereavement on mental health from the effects of socio-economic class on mental health leading to potentially spurious associations being found.

A potential selection bias was gender. Some studies have found men to be reluctant to participate in bereavement research (Stroebe and Stroebe, 1994). Therefore a frequency distribution control method was used (Bowling, 2000) to aim for proportionate numbers of bereaved and non bereaved participants by gender and age category. In addition, the participants were matched by GP and general practice to control for practice differences and geographical location. The method of matching was planned to be done on an 'as and when' basis. That is to say, as bereaved people were recruited into the study, the non bereaved people would be identified from their GP and their general practice.

Table 4.1 Time frame for the administration of each measure

	First interview Three- six months		**Second interview 13 months**	
Questionnaire / measure	**Bereaved**	**Control**	**Bereaved**	**Control**
Demographic information	**Yes**	**Yes**	**No**	**NA**
CIS-R	**Yes**	**Yes**	**Yes**	**NA**
SF-36	**Yes**	**Yes**	**Yes**	**NA**
Social Support Questionnaire	**Yes**	**Yes**	**No**	**NA**
Inventory of Traumatic Grief	**Yes**	**No**	**No**	**NA**
Grief Experience Inventory	**Yes**	**No**	**Yes**	**NA**
Helpfulness' of primary care support	**Yes**	**No**	**No**	**NA**
Questionnaire to GPs	**Yes**	**No**	**No**	**NA**

NA = Not applicable

4.15 Ethical procedures

The study was reviewed by the Southampton and South West Local Research Ethics Committee (LREC) in August 1999, and permission to proceed was initially withheld. There were two main concerns raised in their report: the first was the perceived lack of experience that I had in dealing with bereaved people; the second centred on the principle of non-malificience, that bereaved people might be unduly distressed during the interview and suffer subsequent emotional harm as a result. I met with a representative of the LREC in early September 1999, to discuss ways of resolving these issues. It was agreed that the study could proceed with a sample of five bereaved people after which the results would be reviewed and a decision made by the LREC regarding the continuation of the study. It was outlined that I should familiarise myself with bereavement work and also that a post-interview measurement of the participants' discomfort during the interview should be designed and administered after each interview. The latter would be reviewed by the LREC.

To gain experience in bereavement work I arranged to spend a day with a social worker at a local hospice, and the bereavement service manager of a hospice in Oxford. These visits were particularly helpful and allowed me to develop a better understanding and a deeper insight into the sensitive nature of bereavement.

4.16 Post interview questionnaire

A questionnaire was designed to collect feedback on the interview assessments. This comprised a five item tick box, with additional space for free text written comments (See appendix 9). To ensure an objective assessment of the post interview, each participant was provided with a stamped addressed envelop to return the questionnaire to Dr. Sheila Payne, who agreed to provide a report of the ratings to the LREC. A resubmission of the ethics application with the agreed additional changes resulted in ethical approval for the assessment of the first five patients being granted on 24th September 1999.

4.17 Recruitment of GPs to help with the study

With provisional LREC approval for the first five bereaved people, recruitment of GPs commenced. To achieve this I initially met with a number of researchers in the department of primary medical care to identify local GPs who had previously collaborated in research with the department. This seemed the best method of identifying those GPs with an interest in research who would be most likely to help with the project. A list of 25 GPs in the Southampton area was made and a standard letter sent to them explaining the study and inviting them to help with the research (See appendix 10). After about a week if there had been no response a follow up telephone call was made to each GP to explain the study and ask for their help. In addition the study was presented at the department of primary medical care to raise awareness and promote interest from my GP and researcher colleagues. In total 15 GPs agreed to participate in the research. Ten did not wish to participate for a variety of reasons. The most frequent reason for declining to take part was a lack of time and resources, often due to participation in other projects. However, other reasons were given. For example the Southampton University Practice declined as their list included a disproportionate number of young people (students) and therefore spousal or partner bereavement was a rare event.

4.18 The role of the GP in distributing the letter to potential participants

Each of the 15 participating GPs was asked to identify any bereaved person who was eligible for inclusion in the study and to send one of the standard letters inviting them to participate. The letter was printed on University letter headed paper and explained the reason for contacting the bereaved person and provided details of the study (See Appendix 11). Contact details were included to allow each bereaved person the opportunity of discussing the study with either Professor Kendrick or myself. The letter also enclosed a form for patient's details, a consent form and a pre-paid envelop. Any person contacted by the GP remained anonymous to myself and could only be identified if they returned their details along with their consent form.

4.19 Safeguards following data collection with bereaved people

I was aware that talking with bereaved people about their feelings can provoke an emotional response during data collection and afterwards, when the person is left alone to dwell on the topics raised. Being mindful of this, at the end of each session I offered each person an information leaflet about bereavement (Royal College of Psychiatrists, 1998). The leaflet provided information and a list of useful contacts for bereaved people. I also suggested that should they experience any emotional or physical health difficulties, they should speak with their doctor or if they had any problems or wanted to discuss anything with me then they could telephone me at the department.

4.20 Recruitment issues

Recruitment via GPs commenced at the start of October 1999, but proved to be difficult. Despite numerous telephone calls to remind the participating GPs and their practice managers, no participants were identified between October and December 1999.
After a total of five months, only two people were identified and subsequently interviewed in February and March 2000, respectively. Both bereaved people were identified by the same GP, who had close links with the department and a keen interest in research. However, one person had been bereaved for nine months, which was outside the proposed six months limit, but due to difficulties experienced with recruitment it was decided to include this person.

4.20.1 Alternative sources of recruitment

After consideration of various options, (such as recruitment via hospitals, the Births Deaths and Marriage Registry, local newspapers, and Funeral Directors) I decided to approach Funeral Directors (FDs). I applied to the Southampton LREC and received the Chair's approval in February 2000 to make this addition to the study. Initially 10 FDs were selected from the local Southampton telephone directory and letters were sent to them between March to April 2000 explaining the study. I followed up each letter with a telephone call approximately one week later, and offered further explanation of the study, after which five agreed to help. Of those that did not want to help, two were unhappy with the suggestion of contacting their clients. They argued that as a small family business, they had close relationships with their clients and guarded their privacy. The other three simply stated that they did not wish to take part but provided no reason. Each of the five participating FDs was asked to send a letter (similar to the GP letter see appendix 12) to bereaved people who had lost a spouse or partner in the last three to six months. Once again the person remained anonymous to myself and could only be identified if they returned their details along with their consent form.

4.21 The first five participants in fulfilment of the LREC requirement

Using FDs enabled the recruitment of another three participants, two in April and one in May 2000. However, it transpired that one FD in Southampton had sent the letter along with their funeral invoice to a number of their clients who had not lost either a wife or partner, or were outside the three months post bereavement time frame. One was a 90 years old man who had lost his wife one month earlier, and the other two bereaved people had recently lost their mothers. Although they did not fit the desired inclusion criteria, it was decided as this was a preliminary study to comply with the LREC decision it would be potentially useful to meet with them. All participants consented to participate and at no point during any of the interviews did anyone become distressed or ask to stop the interview. The profile of the first five bereaved people interviewed is shown in Table 4.2.

4.22 Result of the post-interview questionnaire

All of those interviewed completed and returned the post-interview questionnaire. All reported that the study was a good idea and beneficial to other bereaved people. The participants' responses and comments adequately addressed the concerns of the LREC regarding my abilities and the emotional impact of the interview. The questionnaires were analysed by Professor Payne who provided a report for the LREC.

4.23 Continuation of the study

Based on the results of the first five participants in the study and positive feedback received from the post interview questionnaires, the Southampton LREC gave full ethics approval on May 17th 2000. After I had received LREC approval I recruited two non-bereaved (control) patients via one of the GPs. However due to the success with the recruitment of bereaved people from the FDs I decided to focus on them as a source of bereaved people.

4.24 Further difficulties with recruitment

Following the initial success with speed of recruitment via FDs I was hopeful that recruitment would pick up. Another participant was referred in May 2000, bringing the total number of bereaved people recruited by FDs to four in two months.

However, recruitment slowed down and despite regular contact via telephone and letter with the participating FDs, little further progress was made. No one was recruited in June or July. Two people were recruited in August and two in September 2000. In addition to the participants contacted by the FDs, one widow, who was a friend of a participant contacted me with an interest in taking part in the study. She was sent information about the study and consented to take part and was interviewed in August 2000.

4.25 Widening the recruitment area: the inclusion of East Dorset

Following approval from the LREC of Southampton, an application was made to the East Dorset LREC and approval granted in September 2000. As before, I wrote to a total of ten FDs situated in East Dorset. The exact same procedure as before was used, where I sent a letter explaining the study and followed it up about a week later with a telephone call. Unfortunately all ten declined to participate although no particular reason was given.

4.26 Profile of the participants

Attempts to recruit via FDs in Southampton continued. Another participant was identified in October 2000, but despite best efforts no one else was found until January 2001. In sixteen months of recruitment from the start of the project in October 1999 a total of two participants were recruited via GPs, 10 via FDs, and one via the friend of a participant. Table 4.2 shows the profile of all bereaved people who took part.

Most of the participants differed in some ways from the inclusion criteria, but due to the small numbers it was decided to include them as potentially informative interviews. For example, two were outside the age criteria; one widower was aged 86 and a widow aged 47 years old. One participant had lost a close aunt, whom she described as being like a mother to her and because of this close relationship she was included. An error by one of the FDs resulted in a participant being sent a letter approximately a year following her bereavement. However, from a telephone conversation with the widow prior to the interview I had understood that she had been bereaved within the last six months. The actual length of time since the death only became apparent during the interview.

Eight of the 13 bereaved people were interviewed twice. Of those not interviewed participant 3 had died, participant 7 did not respond to both the letters inviting her for an interview and participant 11 had been interviewed at the 12 month following her bereavement. Participant 13 was the last interview performed, shortly after which it was decided to stop the project due to poor recruitment and limited time. A second interview would not have been justified after the termination of the project. Participant 8, who had been recommended by one of the participants, withdrew from the study during the initial interview. She voiced objections to the nature of the questions about her health status and in particular the Inventory of Traumatic Grief. She did not appear distressed or angry about the interview, but did comment that it was not what she had anticipated, referring to the questionnaires used, which she described as pointless. Her belief was that the research would have involved an interview to find out her opinions and feelings about bereavement (her comments are discussed later).

Table 4.2 Profile of bereaved people

ID	The deceased	Gender	Age	Date of first interview	Time from bereavement to first interview	Time from bereavement to second interview	Referred by
1	Wife	Male	65	24/02/00	3 months	14 months	GP
2	Husband	Female	74	10/03/00	9 months	13 months	GP
3	Wife	Male	90	10/04/00	1 month	Deceased	FD
4	Mother	Male	44	17/04/00	2 months	14 months	FD
5	Mother	Female	45	11/05/00	2 months	14 months	FD
6	Husband	Female	70	08/08/00	4 months	14 months	FD
7	Husband	Female	71	20/05/00	2 months	No response to letters	FD
8	Husband	Female	51	30/08/00	4 months	Withdrew from study	Friend of participant 6
9	Aunt	Female	53	31/08/00	2 months	14 months	FD
10	Wife	Male	86	07/09/00	3 months	14 months	FD
11	Husband	Female	47	27/09/00	12 months	No follow up	FD
12	Husband	Female	58	03/10/00	4 months	15 months	FD
13	Husband	Female	55	23/01/01	7 months	No follow up	FD

In total only two non-bereaved control participants were recruited to the study and therefore they will not be described or analysed as their data adds nothing to the research findings.

4.27 Termination of the project.

In December 2000 I sent a letter to the five participating FDs providing them with an update of the study and asking them if they still wished to participate. Of the five, two wished to continue, one FD had taken up a new post and therefore withdrew his funeral service from the study, the remaining two participating FDs withdrew. However, I received one further referral from the FDs (participant 13) who I interviewed in January 2001. Shortly after the interview, I therefore decided to stop recruiting and to inform the two remaining FDs of my decision to terminate this part of the project. The difficulties experienced in the study and the few people recruited had clear implications for the feasibility of a larger study in the future. The low numbers and diverse characteristics of the participants make it impossible to make any generalisations to a wider population of bereaved people, therefore it was decided it was not worthwhile analysing the findings of the 13 bereaved people seen. However, the range of results found for the various measures used could inform a sample size calculation for a bigger study in the future. Therefore I aim to present a critical reflection on the study with suggestions for future research and to discuss what I have learned from the research process.

4.28 Results

The participants comprised nine women and four men. The average age was 62 years (range 44-90 years). No statistical analysis was performed on the data due to the small number of participants and limited use of such analysis. The discussion section (Chapter 7) will present a critical evaluation of the results and methods used, and provide recommendation for the approach to future research in this area. Table 4.3 shows the questionnaires completed by the participants.

Table 4.3 Questionnaires completed by the participants

	Questionnaires completed						
Participant	**Gender**	**CIS-R**	**SF-36**	**GEI**	**ITG**	**SSQ**	**Helpfulness of Primary Care support**
1	**Male**	✓	✓	✓	X	✓	✓
2	**Female**	✓	✓	✓	✓	✓	✓
3	**Male**	✓	✓	✓	X	✓	✓
4	**Male**	✓	✓	✓	X	✓	X
5	**Female**	✓	✓	✓	X	✓	✓
6	**Female**	✓	✓	✓	✓	✓	✓
7	**Female**	✓	✓	✓	✓	✓	✓
8	**Female**	✓	✓	X	X	✓	✓
9	**Female**	✓	✓	✓	✓	✓	✓
10	**Male**	✓	✓	✓	✓	✓	✓
11	**Female**	✓	✓	✓	✓	✓	✓
12	**Female**	✓	✓	✓	✓	✓	✓
13	**Female**	✓	✓	✓	✓	✓	✓
Total		13	13	12	8	13	12

Key: ✓ = Yes X = No.

CIS-R: Clinical Interview Schedule Revised; ***SF-36:*** Medical Outcome Study Questionnaire short form 36; ***GEI:*** Grief Experience Inventory; ***ITG:*** Inventory of Traumatic Grief; ***SSQ:*** Six Item Social Support Questionnaire

Chapter 5 A postal survey of District Nurses

5.1 Introduction

The difficulties experienced in assessing bereaved people promoted a critical reflection which was an impetus to consider ways that I could develop my doctoral research, while maintaining my focus on bereavement support in primary care. Through my reading of the literature I became aware that one area that had received little attention was the involvement of the District Nurse in the provision of bereavement support in the community. I realised that the District Nurse (DN) service was pivotal to the provision of palliative care in the community, and in a recent editorial Payne (2001) suggested that bereavement support had become a fundamental aspect of palliative care. Over recent years, the professional role and responsibility of nursing has been extended and the skill base expanded. Some district nurses carry out bereavement follow-up visits and some provide bereavement counselling or other bereavement services. However, this had received little attention in the nursing and medical literature. I was therefore inspired to focus my research on the DN to facilitate an exploration of this under-researched topic, which I hoped would provide new and exciting information. This chapter will describe the first of those studies.

In February 2002 The British Medical Association (BMA) published a discussion document in which they proposed a model of healthcare designed to overcome the shortages of GPs. In this document they suggest that:

> *"The community nurse would also have an expanded clinical role, undertaking a wider range of interventions and so preventing the need for the patient to always attend the GP surgery or outpatients, or stay in an acute bed unnecessarily."*

The practical implications of the BMA proposal would involve a radical change to the boundaries of the nursing role. Bereavement support may be one area where nurses are required to expand their skill-base, to facilitate a reduction in the increased use of primary health care services following bereavement (Parkes 1964a, Tudiver et al, 1995; Charlton et al, 2001) and to proactively identify people with bereavement related mental health problems.

As a developing profession, nursing needs to acquire an evidence-based for practice in bereavement support. Unfortunately, the results of the literature search suggest that there was little evidence on which to base such practice. Writing on bereavement care, Parkes suggested that it was '*unethical to introduce any kind of service without carrying out research to find out whether it does good or harm*' (Parkes, 1995: p 171). At present, it is unclear what effect if any there is from DN led bereavement support. DNs may have a key role in assessing the needs of the bereaved person, detecting any abnormal pathological grief, helping the individual with the pain of grief, and offering advice, support and information (Costello, 1995; Monroe & Smith, 1997). However, one must question whether it is appropriate for district nurses to invest their time and resources in bereavement support.

My research raises a number of issues because it is part of the broader agenda of ongoing medical, political, and social change. There is currently much debate about the new and emerging role of nursing. The nursing professional body (the RCN) is striving for increased recognition of the professional status of nurses within the health arena, with respect to both financial reward and the development of autonomous specialist roles (e.g. consultant nurses, and endoscopy nurse specialists). While specialist nurses are taking on many of the traditional roles of the junior doctors, there is also a political edge as the European Working Time Directive aims to cut doctors hours and one way to achieve this is to expand the role of the nurse to accommodate the shortfall. Bereavement support also raises the question of whether bereavement should be viewed as a medical or social concern. Problems arising from bereavement can be both, although specific mental health problems such as depression are clearly medical concerns. The DNs role is to support and care for people with a medical problem requiring treatment by the primary care services. However, social care is within the province of the social services, which raises interesting questions about role boundaries and also the funding of bereavement service provision. DNs are key players in the debate about bereavement support in primary care as they would be one of the key health professionals expected to deliver that care. It is therefore important that their views and opinions about bereavement support are sought. In the absence of any published research about the actual involvement of DNs in bereavement support, I decided to ascertain from a representative sample of DNs their current practice and beliefs about bereavement care in the community.

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5.2 Aim of the study

To survey a representative sample of British DNs to ascertain their current practice and beliefs about bereavement care in the community. The main research questions were:

- Do district nurses see bereavement follow-up visits as part of their role?
- What factors are associated with how informed nurses feel about bereavement?
- What factors are associated with the nurses' interest in bereavement?
- What factors influence the likelihood of post bereavement visiting?
- Do nurses perceive post bereavement visits as helpful or intrusive on peoples' grief?
- Do nurses assess bereaved people for mental and physical health problems during follow-up visits and if so how?
- Do nurses offer support and advice to bereaved people and if so what?
- Does a nurse's personal experience of bereavement influence beliefs or professional practice?

5.3 Method

When information is lacking and there is a limited theoretical perspective, surveys can be described as 'atheoretical', whose aim is to describe the population under survey and provide information, which could be used to develop theories.

5.3.1 Survey method

Social survey research is described by Bryman (2001) as research that

> '*comprises a cross-sectional design in relation to which data are collected predominantly by questionnaire or by structured interview on more than one case (usually quite a lot more than one) and at a single point in time in order to collect a body of quantitative or quantifiable data in connection with two or more variables (usually many more than two), which are then examined to detect patterns of association.'*(Bryman, 2001; p 42)

A postal questionnaire was selected as the most appropriate method of collecting data at one point in time for this cross-sectional survey. The design of this questionnaire is described below in section 5.3.4. As the survey intended to describe the practices and beliefs of district nurses, it was specifically designed to be a once only self-administered, cross-sectional postal survey. It would be too costly and time demanding to survey the entire population of district nurses in the UK, so it was decided to survey a sample of district nurses based around the Southern Coastal Region of the UK. This area surrounds the Southampton area, and is local to the researcher.

The main advantage to the postal survey is that it is one of the most convenient ways of gaining a large amount of data from a sample of the population in a short period of time and at a low cost. However, when there is a low response rate it is difficult to generalise the findings and there is the possibility that respondents may be different from non-respondents. There is also the danger that respondents may try and please those conducting the survey by providing the answers they presume are the correct one, which will reduce the validity of the findings. This problem can be reduced by using anonymous questionnaires

5.3.2 Context of the study

The survey was carried out in the central southern coastal area of Britain including the districts of West Dorset, East Dorset (including Bournemouth and Poole), Isle of Wight, and Southampton and South West Hampshire (including Southampton city, New Forest and Romsey).

Southampton City is a major city and port with a population of 216,000. It has a high proportion of 20-29 year olds due to a large concentration of students but also a high proportion of older people in the New Forest district. Three percent of the population is minority ethnic people mainly concentrated in the inner city of Southampton (8% of Central Southampton population). Unemployment in the City and New Forest is higher than the national average, (Southampton and South West Hampshire Health Authority, 2000).

Dorset: The population of Dorset is approximately 382,000. Dorset is a ‘resort and retirement’ area, and has a higher proportion of residents aged 65 years and older (22.1%) than England and Wales (15.8%). There are low numbers of minority ethnic people and unemployment is generally lower than the national average. Bournemouth has the highest rates of unemployment in the county (Dorset Health Authority, 1999).

Isle of Wight: The mid 1996 population estimate was 125,466. The Isle of Wight has the highest proportion of people over 65 years (23.2%) and over 75 years (11.5%), and the second highest proportion of people over 85 years (3.2%) of any English health authority. There are relatively few minority ethnic people, 0.7% compared to 5.5% in Britain. The island has the lowest average male earnings in the South East, with Jarman indicators showing that it is among the most deprived 10% of wards in England, (Isle of Wight Health Authority, 1999).

5.3.3 Sampling frame

In this chapter the term 'district nurse' will be used to describe any qualified nurse, with or without a specific district nurse qualification, who worked in community settings in the target districts. Those excluded were: non-qualified nurses, Health Visitors, Community Midwives, Practice Nurses, School Nurses, Community Psychiatric Nurses, and Occupational Health Nurses. DNs were identified by the district nurse manager in each district from their current employment records.

5.3.4 The questionnaire

Surveys are grounded within the positivist paradigm. They are typically descriptive and seek to describe, analyse or explore the sample population. The data collected are mainly quantitative and used to produce numerical statistical information. However, when open-ended questions or free text questions are used it is possible to collect non-numerical data, which can be analysed using methods such as content analysis. This can be used as a qualitative method in the development of meaningful categories or as a quantitative method to quantify instances of categories within the text. But such questionnaires cannot be described as qualitative research *per se.*

The general topics to be covered reflected my interest in gaining as much information as possible about DN practice, the perceived role of the DN, DN knowledge and training in bereavement support, and information about the general practice where the DN was attached including policies, procedures and available resources. The format of the questionnaire included tick box and circle response as well as allowing open ended free text questions where the DN could elaborate and provide comments and views about bereavement support.

When designing the questionnaire I reviewed a variety of standard questionnaires to gain an overview of the typical structure and format. Both my supervisors had previously developed questionnaires to evaluate bereavement issues and their feedback was valuable in shaping my questionnaire. A first draft of the questionnaire was made which contained five general question areas: demographic information about each nurse; their interest in and education about bereavement; views about bereavement care and the role of the district nurse; normal / usual care provided to bereaved patients at the practice; and information about the general practice with which the nurse had links. This was initially distributed to an academic clinical psychologist with experience of bereavement research, a psychiatrist, two research nurses and two academic GPs for comment. Based on their feedback, repetitive questions were cut out and some re-worded to clarify their meaning. The second draft was then sent for an evaluation of its content validity to a DN Advisor in one of the districts surveyed. The advisor's feedback was positive and she suggested some slight changes to the wording. The final draft was piloted on six people (two nurses, two GPs and two social science researchers) to ensure usability. A copy of the District Nurse postal questionnaire and accompanying letter is provided in appendix 13.

The final version contains nine questions about the nurse's perceived role in bereavement care, requiring the respondent to tick a box on a five point Likert scale, ranging from strongly agrees to strongly disagree. Nine questions provide an opportunity for respondents to provide additional information. There is additional space for the respondents to provide additional comments and feedback on the questionnaire at question D11 and D13 on page 7. In addition, question 7 of the demographic personal information (page 8) asked nurses who had experienced a personal bereavement whether it affected their professional practice. The demographic information about each nurse was put into the final section of the questionnaire. This was deliberate, as some respondents are reluctant to provide information about age, gender and other demographic (personal) information but may have no objections to answering the other questions. Asking potentially sensitive information first may have inhibited some nurses from completing the remaining questions. The final questionnaire had both face validity and content validity as it had been reviewed by a number of experienced researchers including both supervisors and a DN advisor.

5.3.5 Issues of potential bias

In postal surveys the main potential source of bias is non-response bias. It was hoped that a response rate approaching 70% would be achieved. Another potential bias was sampling bias as the sample of DNs may have had particular views about bereavement which may have made it difficult to generalise to a wider DN population. To avoid this I aimed to sample a wide range of DNs across several counties. Two other sources of bias were possible from DNs when completing the questionnaire, namely recall bias and social desirability bias. The former implies that some DNs may have been selective in recalling information about bereavement which may have influenced their responses. Similarly, social desirability bias may occur because the DNs want to present themselves in a particular way regarding bereavement support. Some may have been concerned that the information would be disclosed to their managers or their views used to identify them. Although the accompanying letter to the DNs emphasised that the questionnaire was anonymous this may still have raised concerns for a small number.

5.3.6 Procedure for the survey

A total of 522 questionnaires were mailed to the respective district nurse managers who distributed the questionnaire to the nurses in their districts between February 2000 and September 2000. The total numbers distributed per district were: East Dorset 225, Isle of Wight 65, Southampton 140, and West Dorset 92. The final cut off date for returns was March 2001. Each nurse received a plain brown envelope, which contained a covering letter informing them about the study, the questionnaire and a pre-paid envelope for return of the questionnaire.

5.3.7 Ethical procedures

Prior to starting the study I discussed the ethical requirements of the study with the local representatives of the Local Research Ethics Committee (LREC) responsible for each participating area. All considered the survey an audit of professional practice which did not involve patient contact or data, therefore permission to carry out the study was given.

I was mindful of the need to maintain respondents' anonymity and confidentiality. As no questionnaire had been sent directly by me, all respondents remained anonymous. Two reminders were sent at approximately four and seven weeks. These were distributed to all nurses by the district coordinators. Nurses in West Dorset received only one reminder at 12 weeks due to a delay in distribution. The University policy on data protection was consulted and followed.

5.4 Analysis of numerical data

The Statistical Package for the Social Sciences (SPSS) version 10 (SPSS, 1999) was used for data entry and analysis. Most of the data were categorical, consisting of nominal data (e.g. spiritual belief), dichotomous or binary data (e.g. gender or yes/no answers), or ordinal data (e.g. age categories or the questions about nurses roles which used a Likert scale ranging from strongly agree to strongly disagree). The chi-square statistic was used to determine the significance of associations between categories when the data were binary or ordinal. Of the chi-square tests offered in SPSS the Pearson chi-squared test was selected. When the data were ordinal, the test for linear-by-linear association was used to determine the significance of associations. For example this was used to test associations between reported roles of the district nurse and factors such as age and level of academic achievement.

The chi-squared test and test for linear-by-linear association (for ordinal data) were used to identify variables associated with reported roles of the district nurse, levels of interest in bereavement, feeling informed about bereavement and likelihood of post-bereavement follow-visits. Key variables used in the analysis were age, pre- and post-registration education, employment status, significant personal loss, level of academic achievement, district, professional position, and general practice activities related to death (e.g. keeping a death register). Age was displayed in the following categories: 21-30, 31-40, 41-50, or 51 or older. Ordinal data were also analysed for between group differences using the non-parametric Wilcoxon rank sum test when there were two groups and the Kruskal-Wallis test when there were three or more groups (Siegal & Castellan, 1988).

Logistic regression (Agresti, 1996; Kleinbaum, 1994) is a statistical method that is used to predict the presence or absence of a characteristic or outcome based on values of a set of predictor variables. The characteristic or outcome is a binary variable such as present vs. absent or death vs. survival. The predictor variables are each added to build up a model of the best independent predictors of the selected outcome. For this study logistic regression was used to identify factors independently associated with an interest in bereavement (interested vs. not interested) and a high frequency of post-bereavement visiting (hi frequency visiting vs. low frequency visiting). Generally, variables were selected using forward stepwise selection. However, when thought appropriate, subject matter considerations were used to choose between two competing variables.

5.5 Analysis of textual data

Free comments made by district nurses were analysed using content analysis (Berelson, 1952; Holsti 1969; Krippendorff, 1980; Weber, 1990). Content analysis was selected as it reduces textual data into meaningful categories (Weber, 1990) which Robson (2002) describes as '*codified common sense*' (Robson, 2002. p 352). Classic content analysis is described by Berelson as:

> *'a research technique for the objective systematic and quantitative description of the manifest content of communication'* (Berleson 1952, 18).

This definition of classic content analysis is rooted in communication research particularly the mass media (e.g. newspapers and television). When content analysis is used in a quantitative way, it is systematic, and involves the objective identification, linking and quantification of specified characteristics of the data, which is usually text. Berelson's tight definition has been contrasted with Holsti's more open definition of content analysis, which is described as:

> *'any technique for making inferences by objectively and systematically identifying specified characteristics of the message'* (Holsti 1969: 14).

Berelson's use of the term 'manifest content' suggests uncovering the 'apparent content of the item in question: what it is clearly about' (Bryman 2001: 179). This is broadly within the positivist paradigm in that it largely takes what is given by interviewees as 'the truth', and in that sense it is neither reflexive nor interpretive. When the analysis focuses on the words and sentences used to express meaning it is best described as syntactic content analysis (Andren 1981. p 55). Bryman (2001) suggests that using Holsti's definition:

> "*Essentially opens the door to conducting an analysis in terms of what we might term 'latent content' – that is the meaning that lies beneath the superficial indicators of content*" (Bryman 2001p 179).

From this perspective it is possible to go beyond a simple count of word frequencies and to look at latent and emerging themes within the texts, which involves the researcher working with the text in an interpretative way to develop meaningful categories (Bryman, 2001). In my interpretation of the data I used both a quantitative approach to analysis, to count the frequency of key words within the text, and also a qualitative approach to analyse latent themes and search for meaning within the text. This enabled a richer understanding of the data. Weber (1990) suggests:

> "*The best content-analytic studies use both qualitative and quantitative operations on the text. Thus content analysis methods combine what are usually thought to be antithetical modes of analysis*" (Weber, 1990. p. 10).

5.5.1 Issues of reliability and validity in content analysis

In content analysis there are three types of reliability of relevance: stability (e.g. intra-rater agreement), reproducibility (e.g. inter-rater agreement), and accuracy (the extent to which the classification of the text corresponds to a standard norm) (Krippendorff, 1980). Even within 'classic content analysis' with its objective focus on the 'manifest content' of text, reliability has been a problematic issue (Berelson, 1952; Holsti, 1969; Andren, 1981; Krippendorff, 1980; Weber, 1990). As there was a relatively small amount of text, I typed verbatim each of the DNs comments. This was checked by myself and discussed with my supervisors.

Validity is equally taxing if there are difficulties with basic definitions. As content analysis requires the formation of specific codes with a coding manual, there is room for conceptual differences between two coders, who may perceive the text in different ways due to a variety of reasons (e.g. language of the coder, experience, culture, ethnicity and gender). This affects reliability, as the precise coding of words depends on a clear interpretation of what each word should be coded as. Furthermore, once one goes beyond a simple count of word frequencies to examine the 'latent' content, the potential problems for validity and reliability are compounded. The procedure used to identify text is described below.

5.5.2 Sampling of the written text

Written information was mainly provided at three sections of the questionnaire. The first was question B 6, which asked the length of time nurses should maintain contact with newly bereaved patients, and was outlined earlier in the results. The two other areas are described here and comprise question 7 (personal information on page 8 of the questionnaire), and question 13 (section D, on page 7 of the questionnaire). The research questions were as follows:

- How does a personal significant bereavement affect the way district nurses support bereaved people?
- What are district nurses' views about issues raised in the questionnaire?

All written comments at the selected section were transcribed verbatim and saved to computer as separate Microsoft© (MS) Word documents. All quotes from the participants were identified by a letter to signify the district and a code number to identify the participants. These are presented in 'text boxes'. The recording unit was the occurrence of key words, and the context in which the word was used, because the same word can be used to produce several different meanings. For example *right* can be used in a political sense, a directional sense or a correct sense. During the initial stage of analysis all comments were printed off and read repeatedly to identify key words and their contextual use. At each reading, key words in the text were highlighted and a list of key words was drawn up. To help generate themes, the key words were put into a computer thesaurus used to generate similar words for each context. When an exhaustive list of words had been drawn up and put into related themes, the computer file of the comments was searched for the occurrence of each word in the text using the 'find' facility. The search term used a shortened version of the key word so that similar contextual uses could be identified. For example 'empath' was used to find the words empathy, empathise or empathic. The search identified where in the text each word occurred, the context in which it had been written and which nurse had written it. I identified each section of the text where the key word occurred and copied and saved this to a table in a separate Word document. From the table I could count the occurrence of the word, and identify the nurse who wrote the comment and read the actual verbatim comment. The search continued until all the words in each theme had been exhausted and a separate table for each of the identified themes created.

5.6 Results

The analysis of the numerical data will be presented first followed by the analysis of the textual data. Both results will be integrated into the discussion section presented in Chapter 7. The overall response rate was 62% (323) following two reminders. For all variables chosen for analysis, item non-response was never above 9% and all available cases were used at each stage of analysis.

5.6.1 Demographic profile of the district nurses:

Approximately 5% (16) of the sample declined to provide any personal information. Of the 307 that provided information 302 (98%) were women. The distribution of ages was as follows: 25 (8%) were aged between 21-30, 107 (35%) were aged 31-40, 111 (36%) were aged 41-50, 64 (21%) were aged 51 or older with only one person being over 61 years old. Two hundred and sixty three (86%) were married or living with a partner, 18 (6%) were single, 20 (6%) were separated or divorced, and six (2%) widowed. One hundred and eighty one (59%) were employed full-time and 127 (41%) part-time. The median length of time that nurses had worked as a district nurse was nine years with a range from four months to 30 years.

5.6.2 Information about the general practice where the nurse had links

Most nurses reported regular contact with at least one general practice. Of these 224 (73%) reported that a linked practice kept a death register, 65 (21%) did not know, and 230 (74%) reported that news of deaths was shared with the whole primary care team, mainly via a message book or notice board. A practice link with a bereavement service was reported by 89 nurses (29%), while 93 (31%) said there was no link and 120 (40%) were not sure. CRUSE was the single most frequently named linked bereavement service; others included a local bereavement group, a palliative care unit, Macmillan services and counselling. CRUSE is the leading non-religious charity in the U.K. specialising in bereavement support.

5.6.3 Interest in bereavement

Two hundred and fifteen (69%) indicated an interest in bereavement, and 250 (80%) an interest in palliative care. Two hundred and ten (67%) expressed an interest in both, and 36 (12%) declared an interest in palliative care but not in bereavement care. When asked about how informed they felt about bereavement issues 129 (40%) felt well or very well informed, 143 (45%) informed and 47 (15%) poorly or very poorly informed. Only eight (2.5%) of the 309 respondents were members of groups linked with bereavement care and six (2%) assisted in running a bereavement support group.

5.6.4 Sources of education about bereavement

Of the respondents 316 (98%) provided information about their sources of education about bereavement which is summarized in Graph 5.1.

5.6.5 The role of the district nurse in bereavement care

Table 5.1 provides a summary of respondents' views about bereavement care. When the nurse had cared for a patient who died while on their caseload, 302 (95%) thought that they should visit the bereaved relatives or carers as part of their routine work. Of those district nurses who made bereavement visits at the home of their patient 100 (32%) always visited, 126 (41%) frequently visited, and 76 (24%) occasionally visited; only nine (3%) never visited. Two hundred and sixty three (82%) stated they thought they should maintain contact with the bereaved relatives of the deceased patient through visits, letters or phone calls.

For a 'routine' bereavement visit, 131 (56%) would visit within the first three days of the death and 198 (84%) within the first week. When asked how long they should maintain contact with bereaved relatives the range of responses was from two weeks to over 15 months. In addition, 133 respondents wrote personal comments (see box 5.1). The great majority (78%) suggested that the length of post-bereavement contact should not be prescriptive but tailored to the individual's needs and circumstances.

Graph 5.1
Sources of education about bereavement

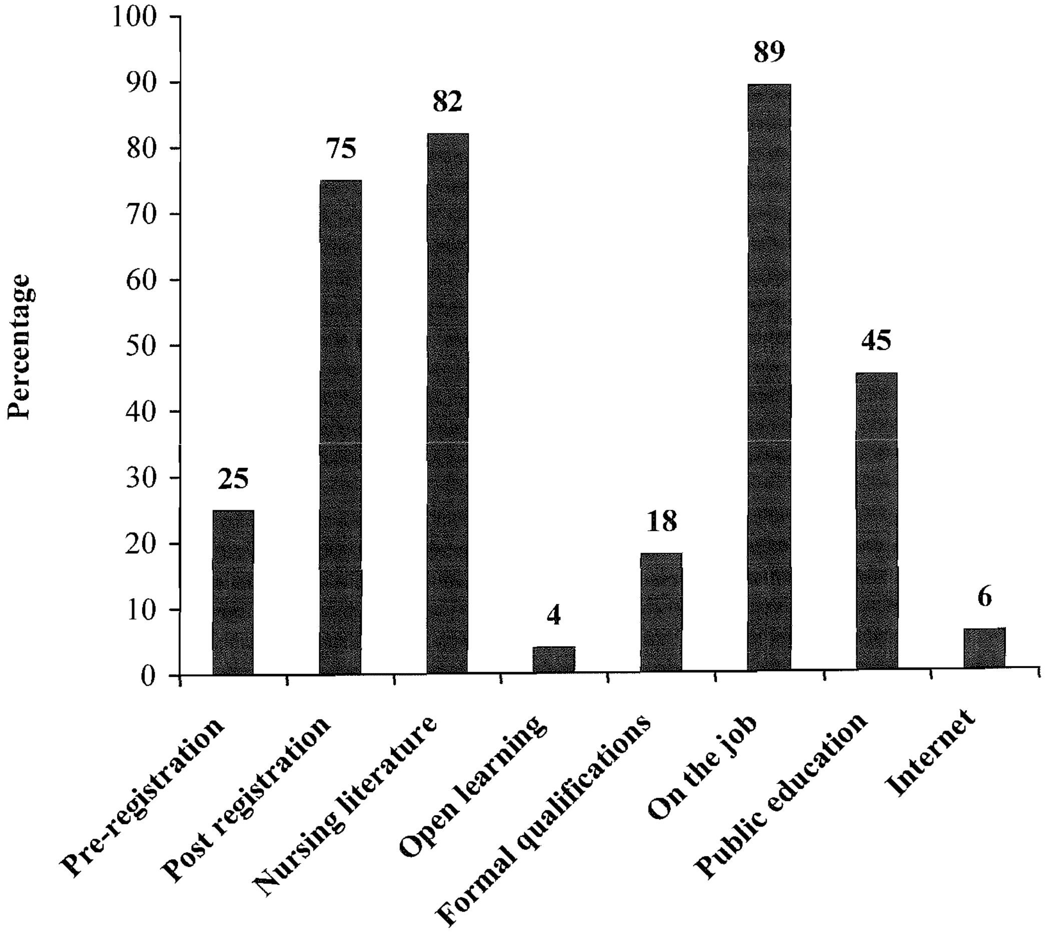


Table 5.1 Respondents' views about bereavement care.

	Number (%) of respondents				
Statement (number of respondents)	**Strongly agree**	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
1. I feel that bereavement visits to relatives of those patients who were on my caseload prior to their death should be part of my routine work as a district nurse (n=319).	**175 (55%)**	**127 (40%)**	**10 (3%)**	**7 (2%)**	**0 (0%)**
2. I feel that bereavement visits to relatives of patients other than those who were on my caseload prior to their death should be part of my routine work as a district nurse (e.g. the suddenly bereaved, who are patients at the practice) (n=319).	**18 (6%)**	**42 (13%)**	**138 (43%)**	**115 (36%)**	**6 (2%)**
3. I feel that visiting newly bereaved patients is intrusive on their grief (n=313)	**5 (2%)**	**26 (8%)**	**93 (30%)**	**166 (53%)**	**23 (7%)**
4. I feel that district nurses should initiate contact with newly bereaved patients (e.g. through visits, letter or phone calls) who were not on the caseload to ensure they are coping (n=320).	**10 (3%)**	**67 (21%)**	**119 (37%)**	**114 (36%)**	**10 (3%)**
5. I feel that district nurses should maintain contact with newly bereaved patients (e.g. through visits, letter or phone calls) who were on the caseload (n=319).	**83 (26%)**	**180 (56%)**	**35 (11%)**	**20 (6%)**	**1 (<1%)**
6. I feel that district nurses have an important role to play in helping bereaved patients to come to terms with their grief (n=320).	**57 (18%)**	**207 (65%)**	**45 (14%)**	**10 (3%)**	**1 (<1%)**
7. I feel that bereavement care is the role of the GP (n=315).	**7 (2%)**	**91 (29%)**	**71 (23%)**	**136 (43%)**	**10 (3%)**
8. I feel that bereavement is best dealt with by the family and not a health professional (n=312)	**2 (1%)**	**38 (12%)**	**90 (29%)**	**164 (53%)**	**18 (6%)**
9. I feel that I have received sufficient training in dealing with newly bereaved patients (n=316).	**12 (4%)**	**127 (40%)**	**54 (17%)**	**111 (35%)**	**12 (4%)**

Box 5.1 Examples of personal comments by DNs

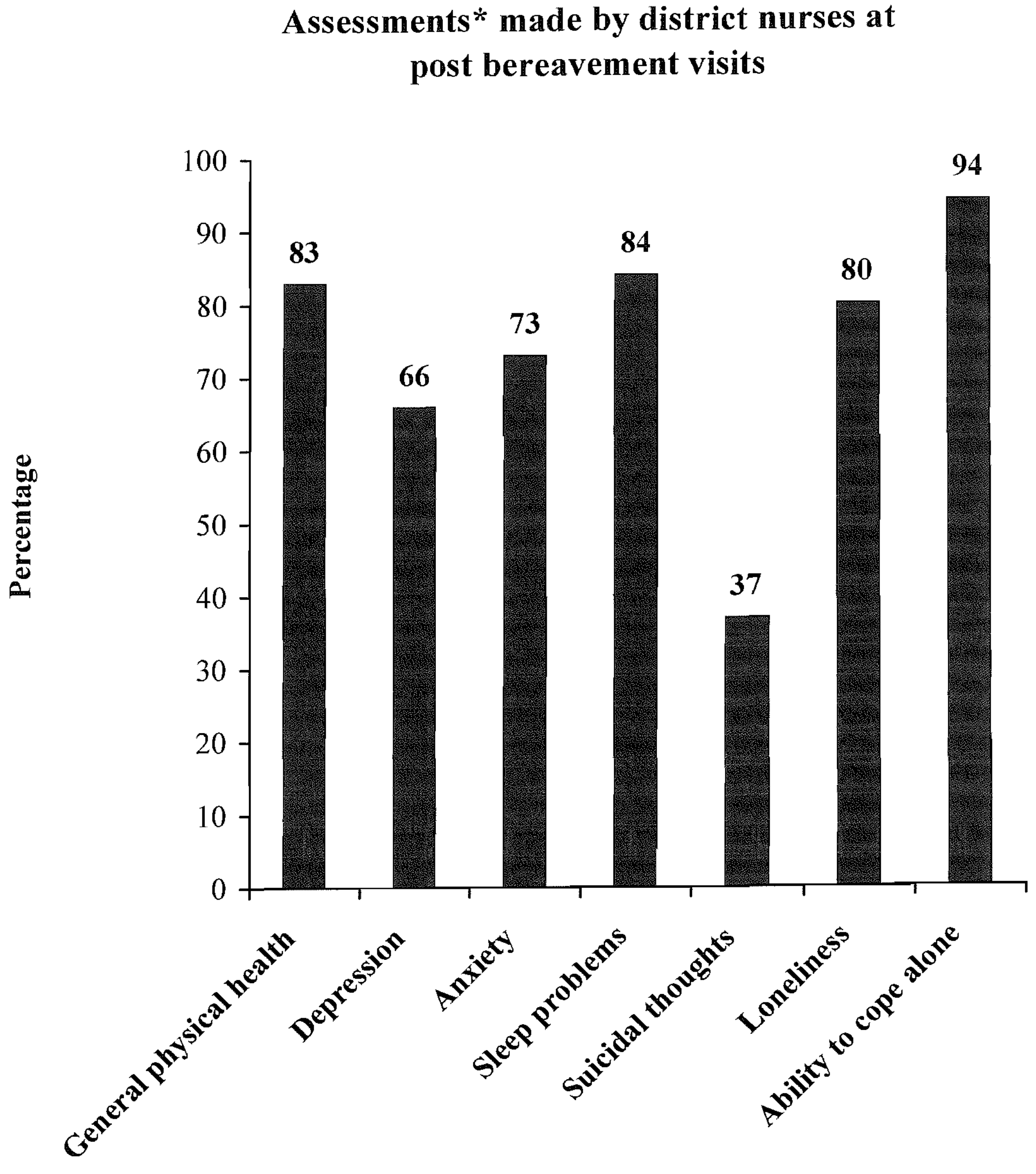
B23	'This varies and has to be according to individual needs.'
C8	'I can't answer this, it's a very individual thing, everyone is different, therefore timings are different.'
E11	'This is difficult to answer, it depends on their own family / friends support, if they have any they may be alone or have poor coping capabilities then they would need weekly visits longer or less depending on their circumstances.'
E36	'This should be patient led, some patients would like to see their district nurse for one month and some for three months. However there is always the danger of making the patient dependent and unable to move on. A fine balance is required.'

Only 31(10%) of respondents thought that bereavement visits to newly bereaved people were intrusive while 189 (60%) considered that they were not. Ninety-three (30%) were uncertain. Two hundred and sixty-four (83%) considered that the district nurse played an important role in helping bereaved people come to terms with their grief, 45 (14%) were uncertain and only 11 (3%) disagreed. Ninety-eight (31%) felt bereavement care was the role of the GP, while 146 (46%) disagreed, and 71 (23%) were uncertain. Forty respondents (13%) considered that bereavement was best dealt with by the family rather than a health professional, 90 (29%) were uncertain, and 182 (58%) disagreed, suggesting the majority felt that bereavement was best dealt with by a health professional.

5.6.6 Post bereavement routine health assessment

Nurses who made a post bereavement visit were asked if they normally assessed their bereaved clients in a number of selected health areas. Graph 5.2 shows the number and percentage of nurses who assessed each specific health problem. Of those district nurses who carried out a post-bereavement visit, 125 (40%) would normally, and 167 (54%) would sometimes, arrange a further follow-up visit. It is noteworthy that 94% of responders would assess the ability to cope while only 37% assessed suicidal thoughts, which may be a feature of bereavement.

Graph 5.2



*Assessment was defined as: 'talking or asking specific questions about the particular problem with the bereaved or a close relative / friend or using an assessment tool to measure any of the given problems'.

5.6.7 The provision of information to bereaved people

Information was sought about the provision of information by any health professional verbally or in writing to bereaved people for the following:

Grief, emotions and feelings, experienced during bereavement: 141 (45%) said information was provided while 139 (44%) said it was not and 34 (11%) didn't know.

Services or organisations available: 196 (64%) said information was provided to bereaved people, 44 (14%) said it was not and 66 (22%) didn't know.

Practical considerations following a death: 164 (53%) said practical information was provided, 68 (22%) said it was not and 78 (25%) didn't know.

Most information was provided by the district nurse in the form of a booklet or leaflet.

5.6.8 The funeral

Twenty-nine respondents (9%) had helped bereaved relatives or friends with funeral arrangements. Only 60 (19%) said it was 'usual' for a representative from the practice to attend the funeral, 224 (71%) said this occurred 'sometimes'. Representation was usually by the district nurse and seldom by the GP, as far as the nurses were aware.

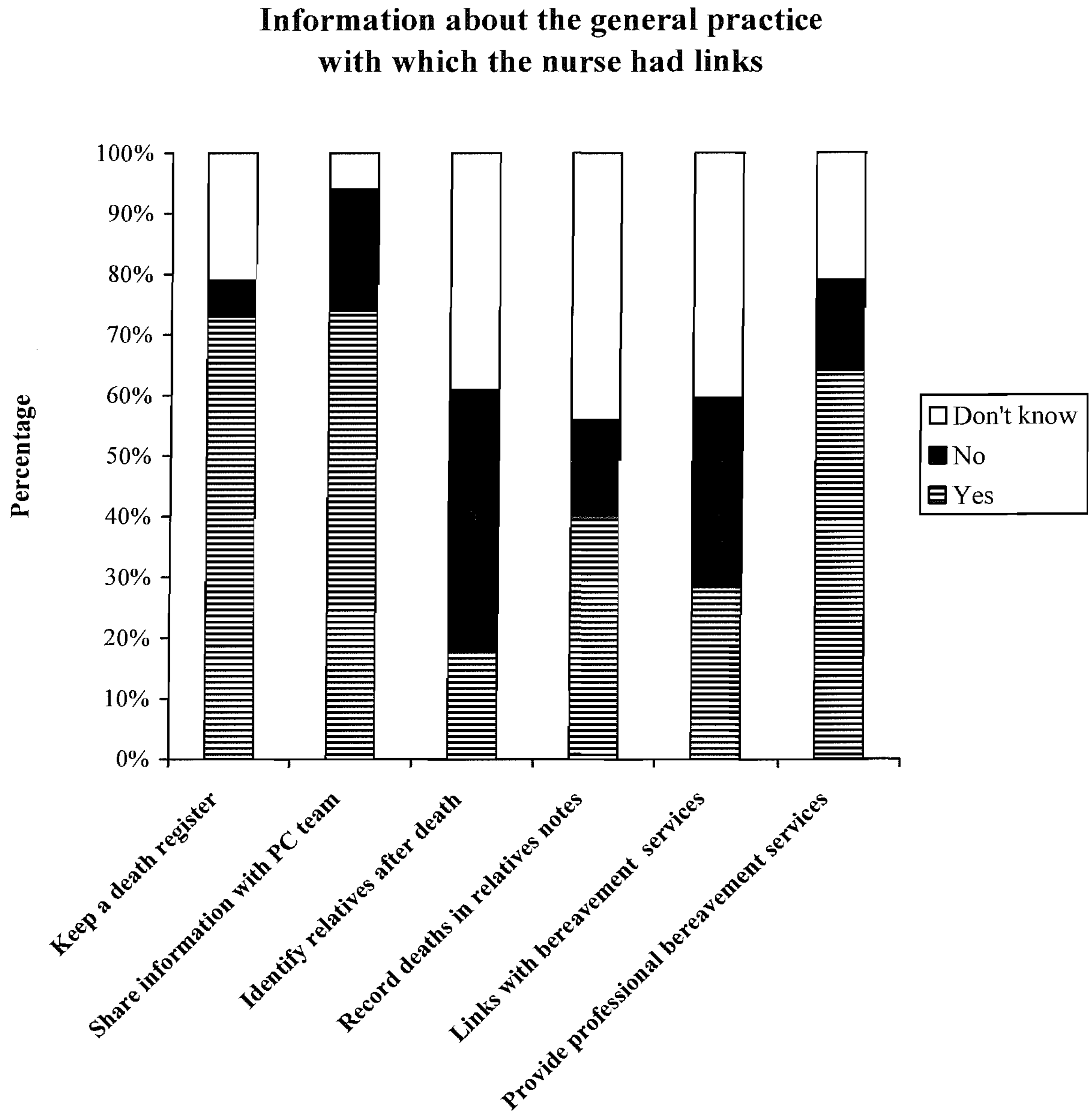
5.6.9 When the bereaved person has no prior contact with the DN.

When the deceased had not been a patient cared for by the nurse (e.g. in the case of a sudden death at home or in hospital) only 60 (19%) stated that a bereavement visit should be their responsibility, while 138 (43%) were uncertain and 120 (38%) felt that no visit should be made. However, 77 (24%) indicated that district nurses should initiate contact with newly bereaved people to ensure they were coping, 119 (37%) were uncertain and 124 (39%) disagreed.

5.6.10 Information about the general practice with which the nurse had links

Graph 5.3 summarises information about the general practice with which the nurse had links, from the nurse's knowledge of the practice. Some nurses had links with two or more practices and others had no specific contact with any one GP practice, due to working 'twilight' shifts or bank work (where they may work across a number of districts).

Graph 5.3



Based on responses to the following question: Does your practice:

- keep a death register?
- share information about deaths with the whole primary care team?
- have a policy for identifying relatives after a patient's death?
- routinely record patients' deaths in the notes of spouses/partners?
- have any specific links with any bereavement service?
- provide the services of a professional psychologist / counsellor who can deal specifically with patients who have been bereaved?

5.6.11 Factors associated with how informed nurses felt about bereavement.

Five variables were examined as potentially associated with how informed nurses felt about bereavement: interest in bereavement, post registration education, level of academic attainment, significant personal loss, and age. Being better informed was associated with having an interest in bereavement ($\chi^2 = 38.66$, df= 2, $P<0.001$), attending post registration courses about bereavement ($\chi^2 = 35.85$, df= 2, $P<0.001$), having a diploma or degree ($\chi^2 = 16.63$, df= 8, $P<0.033$), and having suffered a significant personal loss ($\chi^2 = 7.61$, df= 2, $P<0.022$). There was a significant linear association between age and how informed nurses felt, with a higher proportion of those over 40 years perceiving themselves to be well or very well informed (linear-by-linear association = 10.34, df= 1, P=0.001). However there was a highly significant association between age and personal experience of bereavement (linear-by-linear association = 20.49, df= 1, $P<0.001$), which indicates age may be a potential confounding variable.

5.6.12 Variables associated with nurses' interest in bereavement.

Four variables were found to be significantly associated with an interest in bereavement: an interest in palliative care ($\chi^2 = 145.24$, df= 1, $P<0.001$), post registration education about bereavement ($\chi^2 = 10.35$, df= 1, P=0.002), district ($\chi^2 = 24.14$, df= 10, $P<0.005$), and age (linear-by-linear association = 15.23, df=1, $P<0.001$). Those aged 51 years and older were more likely to have an interest in bereavement and those under 41 years least likely. Pre-registration education, personal bereavement and level of academic qualification were not significantly associated with greater interest. Based on the results of the bivariate analyses and subject matter considerations (discussed with both supervisors) the following variables were included as potential explanatory variables in a logistic regression model for interest in bereavement (yes = 1, no = 0): post registration education, age, significant bereavement, district, and highest academic qualification. The selected model identified two significant predictors: age (LR = 14.93, df= 3, P=0.002), and district of employment (LR = 23.68, df= 10, P=0.009). Table 5.2 presents the estimated coefficients, standard errors and odds ratios with 95% confidence intervals for the selected model.

Table 5.2 Estimated coefficients, standard errors and odds ratios with 95% confidence intervals for the selected model

	Interest in bereavement			**Post bereavement visit**		
Variable	Coefficient	Standard error	Odds ratio (95% CI)	Coefficient	Standard error	Odds ratio (95% CI)
Constant	-0.88	0.89	-	-0.99	1.01	-
District						
1	0	-	1	0	-	1
2	0.81	0.86	2.25 (0.41, 12.2)	1.07	1.04	2.92 (0.38, 22.5)
3	-0.14	0.81	0.87 (0.18, 4.3)	-0.45	0.92	0.64 (0.11, 3.8)
4	0.32	0.82	1.38 (0.27, 6.9)	0.46	0.94	1.59 (0.25, 10)
5	0.73	0.86	2.07 (0.39, 11.01)	-0.63	0.93	0.53 (0.09, 3.3)
6	0.41	0.96	1.51 (0.23, 9.8)	-0.32	1.03	0.73 (0.1, 5.5)
7	0.04	1.04	1.04 (0.14, 7.9)	5.99	11.66	∞ *
8	-0.52	0.99	0.60 (0.09, 4.1)	2.23	1.20	1.25 (0.12, 13)
9	-0.19	0.85	0.83 (0.16, 4.4)	-0.59	0.95	0.55 (0.09, 3.6)
10	2.88	1.28	**17.8 (1.5, 218)**	2.13	1.35	8.45 (0.61, 118)
11	0.89	0.82	2.45 (0.49, 12.1)	0.26	0.92	1.29 (0.21, 7.9)
Age						
20-30	0	-	1	0	-	1
31-40	0.91	0.50	2.49 (0.94, 6.56)	1.16	0.52	**3.19 (1.15, 8.8)**
41-50	1.58	0.51	**4.84 (1.8, 13.1)**	1.17	0.52	**3.21 (1.15, 8.9)**
51+	1.80	0.57	**6.05 (2, 18.6)**	2.19	0.63	**8.90 (2.6, 30.5)**
Academic Level						
EN / RGN	Not applicable	Not applicable	Not applicable	0	-	1
Dip/Degree				1.07	0.29	**2.91 (1.64, 5.2)**

∞ (infinity) * **Since all nurses in district seven were in the high category for visits.**

Bold typeface identifies those odds ratios where both endpoints of the 95% confidence intervals are greater than one, i.e. the variable remains a predictor at the 5% level of significance.

5.6.13 Factors that influence the likelihood of post bereavement visiting.

Nurses who always or frequently visited bereaved people in their homes were categorised as 'high' visitors and those who occasionally or never visited as 'low' visitors. A low likelihood of making a bereavement visit was associated with being employed part time ($\chi^2 = 8.16$, df = 1, P=0.006) and with district of employment ($\chi^2 = 25.62$, df = 10, P=0.003). Factors linked with a high likelihood of making a bereavement visit were: having a diploma or degree ($\chi^2 = 15.40$, df = 1, P< 0.001), having an interest in bereavement ($\chi^2 = 5.77$, df = 1, P=0.019), awareness of a death register at the GP practice ($\chi^2 = 10.21$, df = 2, P=0.005), and age of the nurse ($\chi^2 = 8.20$, df = 1, P=0.005). Those aged 51 years and older were most likely to visit, and those aged 20-30 least likely. A significant personal loss was not associated with a greater likelihood of bereavement visiting. To assess the influence of experience of working as a nurse I investigated the association between visiting (high, low) and the continuous variables: years qualified as a nurse, length of time in current post, and length of time working as a district nurse. Due to the non-normal distribution of the continuous variables, the non-parametric Mann-Whitney U test was used. Nurses who always or frequently carried out post bereavement visits had been qualified as a nurse longer ($P=0.008$), had been employed as a district nurse for longer ($P<0.001$) and had been in their current post longer ($P<0.001$). However, all these variables were highly correlated with age (Spearman's rho $P<0.001$), suggesting that age may be a confounding variable, in that older nurses would be more likely to have been qualified longer and to have worked in their current post longer.

Based on bivariate analysis and subject matter considerations, the following variables were included as potential explanatory variables in a logistic regression model for post-bereavement visiting (high = 1, low = 0): age, district, interest in bereavement, and level of academic qualification. The final model included district ($LR = 25.94$, $df = 10$, $P=0.004$), age ($LR = 13.34$, $df = 3$, $P=0.004$) and academic qualification ($LR = 13.77$, $df = 1$, $P< 0.001$ (see Table 6.2 above).

5.6.14 Variables associated with nurses' roles

The results from the univariate analysis of nurses' views about their role in bereavement care were reviewed and those responses that indicated a range of opinion were selected (see Table 5.1). This is because there was little point in analysing factors associated with responses where the group was largely polarised, such as in statement 1, where 95% of respondents either agreed or strongly agreed that bereavement visits were part of their routine work. Two outcome variables (statements 2 and 9) were selected for analysis against seven potentially explanatory variables: age, interest in bereavement, 'high' and 'low' visiting rates, experience of significant personal bereavement, highest level of academic achievement, how informed nurses felt, and post registration education. Nurses' views in favour of visiting the family of patients not previously cared for were associated with an interest in bereavement ($\chi^2 = 11.39$, $df = 2$, $P=0.004$), and higher level of academic achievement ($\chi^2 = 16.38$, $df = 8$, $P<0.031$). Nurses' views of having received sufficient training in dealing with bereaved people were associated with an interest in bereavement ($\chi^2 = 20.94$, $df = 2$, $P<0.001$), high visiting rates ($\chi^2 = 20.96$, $df = 2$, P<0.001), experience of significant personal bereavement ($\chi^2 = 6.45$, df = 2, P=0.037), being informed about bereavement ($\chi^2 = 107.73$, df = 4, P<0.001), and having undergone post registration education ($\chi^2 = 31.21$, df = 2, P<0.001).

5.7 Results of the analysis of textual data

5.7.1 The impact of personal bereavement on DN practice

Of the 307 responders, 221 (72%) had experienced a significant bereavement and, of those, 165 (74%) said this personal loss had affected the way they cared for and supported bereaved people. To support this, 156 (95%) also provided written comments. The data revealed two relevant themes that described how personal bereavement had affected DN practice, namely a sense of empathy for bereaved people and a perceived improvement in nursing skills.

5.7.2 A sense of empathy for bereaved people

Repeated reading of the texts identified the occurrence of two key words, namely empathy and understanding. These terms were amalgamated into the general concept of '*empathy,*' which is defined as *'the power of understanding and imaginatively entering into another person's feelings'* (Colins English Dictionary, 1985: 480). Through the experience of their personal bereavement, the nurses reported an increased understanding of the experiences of the bereaved person and an increased empathy with their feelings. Using the method described above, the document was searched for key words related to empathy and understanding. The search terms used were 'empath' so as to locate empathy, empathic and empathise, and 'underst' to locate understand and understanding. Sixty one (39%) nurses had written the word *empathise* or *empathy* in their comments and 42 (27%) nurses had written the word *understanding* (excluding those who used the words empathy or empathise). These themes were grouped together and exemplars selected that would best describe the selected category. The remaining 53 (34%) non-selected comments were re-read and themes identified. Of those five (3%)were identified as describing empathy without actually using the word, and another 17 (11%) were also identified as being related to empathy and understanding through their use of words such as insight, awareness, sensitivity, and relate. All 21 (14%) comments were included under the theme of 'empathy', which taken together accounted for 124 (80%) of the nurses comments.

Examples: of comments that used the term empathy

B4	Having suffered three bereavements of very close relatives I feel I can empathise with how the families feel.
C52	I empathise particularly with loss of relative with cancer. I understand the need to have support through the whole bereavement process. I understand the need to listen not talk.
F12	Being able to empathise with bereaved patients experiencing similar feelings re loss.

Examples of comments describing empathy, without using the word 'empathy'.

E34	Having experienced a very traumatic death I had to come to terms with my own grief and guilt. I always try and put myself in the other persons place

Examples of comments using the term understanding

B13	When you have experienced bereavement you understand the pain.
D16	I understand the emotions that are about, one minute OK next in tears wanting to talk about the person – not thinking that they do not exist. Wanting company unable to make any decisions for a while. I find it easier to talk to people about their loss, understand how they feel.
G8	I feel I understand how bereaved people feel and what they can expect from the grieving process. I can also make suggestions of how to overcome the problems

Examples of comments using words such as insight, awareness, sensitivity, and relate.

B16	It has increased my awareness of how a bereaved person can feel.
C25	Aware of initial feelings following bereavement – award of how individuals deal very differently with their emotions and have different needs.
D24	I was very involved with this relative's care over a number of years until they died. I feel I am more sensitive towards carers and try to prepare them for bereavement and explain the care we give before and after a patient has died

5.7.3 An improvement in nursing skills.

A second related theme to emerge was termed 'improved skills'. Eleven nurses (7%) made comments about how the experience of their bereavement had improved the way they dealt with their bereaved clients. Seven nurses (4%) outlined ways that their bereavement had influenced their care, particularly in the way they supported their bereaved clients, and four (3%) specifically suggested that it had improved their listening skills. This links with empathy as some conceptualised it as a communication process (Kunyk & Olson 2001).

Example of comments that suggested it had generally improved support or care.

B24	My experience of the loss of my father has only confirmed to me that the way I support my patients in the right way. I never really underestimated the value of support to families during this time
D34	As a community nurse I am now much more conscientious of terminal care given. Pts and carer need to feel they have maximum care. It will reduce guilt afterwards if they were able to give the best care.

Example of comments that suggested it had improved their listening skills

H7	improved my listening skills. Knowing what not to say
J3	I listen more – Allow periods of silence to make more time at a point in the day where I am least likely to be disturbed so the patient has my undivided attention.

5.7.4 General comments and issues raised by the questionnaire

Of the 323 responses, 106 (33%) nurses wrote general comments about bereavement support. An analysis of the data identified four main themes: the assessment of needs of the bereaved people, the relationship between the bereaved person and DN, constraints on the DNs role in bereavement support, and variations in practice

5.7.5 The assessment of needs of bereaved people.

Overall 42 (40%) nurses commented on the needs of bereaved people. Thirty two (30%) of nurses used the key words 'need', 'assess' or 'support'. In addition 10 nurses (9%) commented on the referral of bereaved people to other resources such as CRUSE (key search term 'refer'). Most cautioned against a prescriptive approach to support and advocated an assessment of individual needs, based on individual circumstances. This was also the main theme identified from the personal comments written by nurses in response to the question about the role of the district nurse, where 78% suggested that bereavement support should not be prescriptive but tailored to the individual's needs and circumstances. The individual nature of bereavement and the different needs of their clients are identified by nurses as a key aspect in their provision of support. However, it is not clear how nurses tailor their support to client needs and what guides them in that process.

Examples of the assessment of needs of the bereaved people

C31. Bereavement is a very private matter. I firmly believe that not every patient's relatives want too many follow up visits. I assess carefully the situation of each individual, and circumstance.

C42. Bereavement support depends on the individual involved; some need more support than others

B12. Our time restraints only allow us to follow-up those on our caseload. We assess everyone individually some people decline any further visits other like one or two follow-up visits. We assess their support network and refer them to other agencies as needed

The comments by nurse B12 (above) link to two other important themes, namely the relationship already established between the district nurse and family or carer prior to the death, and the practical constraints perceived by district nurses in their role of bereavement support.

5.7.6 The relationship between the DN and the bereaved person.

The relationship between the nurse and the bereaved person was discussed by 24 (23%) nurses. An established prior relationship was seen as an important aspect of nursing care and contact with newly bereaved people without prior contact was sometimes described as an uncomfortable situation. Concerns were raised about both time constraints on district nurse time and a potential lack of appropriate skills in dealing with bereaved people who were unknown.

Examples of the need for an established prior relationship between the bereaved person and district nurse.

E6 I feel that this is very individual and the bereavement support is dependent on the relationship built prior to death and the identified need for support following death

I16. The care bereaved patients get varies according to the relationship already established with that patient / or the amount of care involvement the DN team has had with the patient. As a professional I am always cautious about how involved I get and not getting out of my depth! or having people become reliant upon me. It would be wonderful if there was more support . Counsellors to refer people to.

In the survey 81% were either against or uncertain whether they should visit bereaved people not previously cared for by them. DN E24 encapsulated this view and also raised concerns about the lack of appropriate skills in dealing with bereavement.

E24. I feel very strongly that it is not the role of the district nurse to visit those who have been bereaved but were not receiving DN visits prior o the bereavement. We do not have appropriate skills or numbers of staff to deal with this kind of demand. On the occasions I've been asked to visit following bereavement and the family have not been known to the team both myself and the patient have found this intervention intrusive.

5.7.7 Constraints on the DN role in bereavement support.

A third theme was identified as being the constraints that nurses felt on their role in bereavement support. The main constraint discussed by nurses was a lack of time to deal with bereaved people and a lack of appropriate skills and training to assess and support their needs. The word 'time' was used by 23 (22%) nurses in that context.

Examples of lack of time to perform bereavement visits

E21 From a DN perspective, having time to visit bereaved pts appears to be a big problem. We sometimes do not have time to go to a funeral of a pt that we have nursed over long periods which I feel is often sad for nurses.

B12 Our time restraints only allow us to follow-up those on our caseload. We assess everyone individually some people decline any further visits other like one or two follow-up visits. We assess their support network and refer them to other agencies as needed.

E14 ...I think the way DN services are organised it would be impossible to offer true bereavement care within the high demands of service. There is not enough time.

5.7.8 Appropriate skills and training

In addition to the views outlined above (DN E24), others also raised concerns about their perceived lack of skills and training in bereavement support. One DN (E36) voiced a particular concern about the lack of training in dealing with young children who were bereaved, which she suggested required specialist input.

Examples of lack of training in bereavement support

C7	I feel that we could do with study days on bereavement as I have received no training at all since 1991, when I started training.
E12	I feel that often we as District Nurses do what we can owing to strain on resources & insufficient training or confidence in dealing with bereavement. There is a tremendous need for more counselling and often clients will 'open up' and be able to grieve years after a loved ones death when we really visited to check a BP or whatever. Such an enormous task to take on our case load though.
E36	Because so many of our patients are elderly we are ill equipped to care for bereaved children. Sadly we have a young adults who she and we have no training to deal with their young children and no identified resource to whom we can refer.

5.7.9 Variations in practice

Variation in practice was discussed by 11 (10%) nurses. The key words identified were: 'dealt', 'continuity', 'patchy', 'pot luck', 'development', 'cancer', and 'hospice'. Another interesting finding was that the reported quality and amount of support was sometimes perceived as being related to diagnosis. It was reported that those with links to hospices received the most support and that people with cancer also received additional support from the various cancer charities.

Examples of variations in practice

D4	Experience has shown that working in different G.P. surgery's bereavement is dealt with in many varying ways within the DN team from very good to poor.
E21	Pts who have spouses who perhaps die of cancer appear to be better supported than other pts. ie Hospice bereavement services. there is inequality in the services.
E24.	In our area it is very prominent that cancer patients/ those involved with the hospice (MS, MND, HIV+ve) receive more help / counselling than others. There appears to be no equity of services for those who are dying and diagnosis is the key to whether patients receive good palliative care and bereavement care

5.8 Discussion

The survey provided an overview of the views and practice of district nurses regarding bereavement support and as far as could be ascertained was the first reported survey of DNs role in bereavement support. The results will be evaluated in the discussion section (Chapter 7).

Chapter 6 Interviews with District Nurses

6.1 Introduction

The postal survey of district nurses raised many interesting questions. However it was not designed to provide an in-depth exploration of those areas. This chapter draws upon that study and continues its exploration and description of the DN service in bereavement support. It uses a qualitative methodology to capture a more detailed 'richer' account of DNs views, beliefs, values and motives about bereavement and their opinions of what bereavement support should be provided by the DN service.

6.2 The study

6.2.1 Aims

The aims of this study were to explore district nurses' experiences of bereavement, their attitudes towards bereavement support and their views about the role of district nurses in providing bereavement support in the community. The generation of theory was thought to be an unrealistic aim, as the sample group was small and time was limited. However, it was hoped that it would generate new questions which could then be addressed through further quantitative research in an inductive-hypothetico-deductive circle.

6.2.2 Objectives

- to explore what district nurses report they do following the death of one of their patients
- to explore the factors that district nurses use to guide them in their practice regarding bereavement support
- to explore the principles that guide district nurse decision making about bereavement support.
- to increase understanding of how district nurses conceptualise bereavement support.
- to explore the personal and professional boundary issues of district nurses in relation to bereavement support.
- to explore district nurses' knowledge of bereavement.

6.2.3 The research questions

There were four main questions:

1. *How do the district nurses conceptualise their role and practice in bereavement support?*
2. *What guides the district nurse in assessing bereaved people and providing support?*
3. *What guides the district nurse when deciding to stop bereavement visits?*
4. *How do district nurses maintain their professional and personal boundaries when dealing with bereaved people?*

6.2.4 Participants and Setting.

The participants comprised 22 trained nurses working in the community as DNs anywhere in the geographical boundaries of East and West Dorset. These two areas were chosen because the district nurse survey described in Chapter 5 had been carried out there, which provided both knowledge of the area and contacts with district nursing managers. The latter were essential for gaining access to district nurses.

6.2.5 Sampling techniques

In qualitative research the consideration of the sample size is not driven by absolute numbers but rather by the purpose of the study, the quality of information obtained in the 'sampling unit' or 'case', and the likelihood of achievement of theoretical saturation (Strauss and Corbin, 1990). In this study the 'case' was defined as the DN. Patten suggests:

> *'Sample size depends on what you want to know, the purpose of the inquiry, what's at stake, what will be useful, what will have credibility, and what can be done with available time and resources'* (Patton, 1990, page 184)

Kvale (1996) argues that researchers should interview as many subjects as necessary to find out what they need to know; however available resources can be a major limiting factor when designing a study. There were three main restrictions placed on this research, namely time, money and the availability of DNs. In positivist research, large representative random samples are used to enable generalisations to be made to the population from which the sample is taken. However, generalisability is not the purpose of qualitative research as observations are grounded within the context in which they occur. Rather it is the transferability of the findings to other contexts that is the concern of qualitative research. Transferability was described in Chapter 3. Four methods of sampling were used to identify the 22 DNs: purposive sampling (3), snowball sampling (3), opportunistic sampling (2), and random selection by DN managers (14).

Purposive sampling or theoretical sampling is a means of selecting those respondents considered to be 'information rich' because of their experiences of, or relationship with, the phenomena being studied (Patton, 1990). Purposive sampling was used to obtain the first three DNs. Following the district nurse survey these nurses had written to me expressing their interest in the study and bereavement care in general. I invited them to be interviewed about their experiences of bereavement support. The three DNs were believed to be potentially information rich respondents due to their interest in bereavement support.

Snowball or chain sampling is a procedure that identifies people of interest from other people who are information rich cases or from other sources and is a recognised method of sampling in qualitative research (Miles and Huberman, 1994).
I asked each of the three purposive interviewees to identify one DN colleague for me to contact. It was emphasised that they did not necessarily have to hold the same views as themselves and that I wanted to interview nurses with many diverse views and experiences. Each participant identified one of their colleagues who agreed to be interviewed.

Opportunistic sampling as the name implies is where the researcher follows new leads and takes advantage of the opportunity. Two further DNs working in East Dorset were identified by academic colleagues, who were participating in research linked to my department.

Another method used was *random selection by DN managers.* This was essentially a way to gain a wide variety of views across a range of different DNs without selecting on specific grounds or belief about bereavement support. By using this method it was hoped to capture a wide range of views from DNs. These participants were identified through the DN managers in East and West Dorset with whom I had corresponded during the district nurse survey. Each manager was sent a letter explaining the purpose of the study and asking permission to contact a sample of district nurses in their area. I followed up each manager with a phone call and as a result one manager in East Dorset provided ten names and a manager in West Dorset four names. Each name was taken from their list of district nurses which covered a wide area. The choice of district nurse was made by the manager. Each manager reported that the names were selected as they occurred on the list, subject to availability and that no nurse was purposefully selected due to any known views about bereavement or association with bereavement research or support. Therefore, the views of these potential participants were unknown to either the identifying manager or me, which reduced any possible risk of bias.

All of the 14 DNs agreed to participate in the study. Table 6.1 shows a profile of the DNs interviewed. All participants were female, aged between 28 and 60. The number of years qualified as a nurse ranged from 7 to 37 years and the number of years working in the community ranged from 1.5 to 27 years.

6.2.6 Ethical considerations

Approval was granted by both the East and West Dorset Local Research Ethics Committee.

Table 6.1 A profile of the district nurses interviewed

Participant	Age group	Nursing grade	Years qualified as a nurse	Number of years worked in the community	Number of years in current post	Degree or diploma	Method of recruitment	length of time of interview in minutes (rounded up)
1	20-30	E	7	1.5	1.5	Yes	Purposive	25
2	31-40	E	17	7	4	No	Snowball	18
3	51+	G	32	27	10	No	Snowball	46
4	41-50	E	22	3	3	Yes	Purposive	20
5	31-40	E	16	6	1	No	Purposive	44
6	51+	G	37	27	8	Yes	Snowball	34
7	31-40	E	16	4	2	Yes	DN Manager	24
8	41-50	G	29	10	10	Yes	DN Manager	20
9	31-40	G	18	12	2	No	DN Manager	27
10	41-50	G	20	13	13	No	DN Manager	17
11	31-40	E	11	5	5	No	Opportunistic	36
12	41-50	E	25	18	1	No	Opportunistic	37
13	31-40	G	14	4.5	1	Yes	DN Manager	33
14	51+	E	31	11	6	No	DN Manager	51
15	41-50	H	24	11	8	Yes	DN Manager	28
16	41-50	H	25	18	18	Yes	DN Manager	38
17	41-50	G	24	15	12	No	DN Manager	15
18	51+	G	37	19	10	Yes	DN Manager	29
19	41-50	E	25	6	6	No	DN Manager	26
20	51+	E	30	5	5	Yes	DN Manager	18
21	41-50	G	25	15	8	Yes	DN Manager	39
22	51+	H	34	21	19	No	DN Manager	42

6.3 Data collection

It took seven months to recruit and interview all 22 DNs. The first interview took place on Wednesday 7th March 2001 and the last on Monday 24th September 2001.

Several methods could have been used to obtain these data including using a focus group, non-participant observation, and interviews. I chose the qualitative semi-structured face-to-face interview as the most appropriate method of gathering the data. This method of inquiry seeks to understand meanings from the participant's perspective (Kvale, 1996), with the interviewer as the main research 'tool'. There are three broad types of interview; structured interviews, semi-structured interviews, and in-depth interviews (Britten, 2000). Structured interviews use short specific questions, which allow the interviewee little choice in response. Conversely in-depth interviews have little structure and minimum interviewer control. Semi-structured interviews are somewhere in between these two methods and use a loose structure based on an interview schedule, that defines the area of interest. There were a number of advantages to using a semi-structured, face-to-face interview to carry out this research on a sensitive topic. On a practical level the choice of individual interviews enabled me to access busy DNs. Although there is a potential economic advantage to telephone interviews, this method was not considered appropriate, as I felt it was important to be present to develop a rapport with each participant and to observe for non-verbal behaviour. I would also be able to provide appropriate verbal and non-verbal feedback when asking sensitive questions (Britten, 2000). Body language is an important aspect of communication and being able to interact with the interviewee can help to enrich the interview.

6.3.1 The interview schedule

The purpose of an interview schedule is to provide a framework to the interview and to elicit responses from the participant. The schedule generally comprises a series of questions and prompts, which are used to guide the interview to ensure the same areas are covered in each interview. While it is designed to act as a prompt to encourage the exploration of themes, it is also broad and flexible enough to allow other relevant areas to be explored should they arise during the course of the interview. The schedule was developed in part from the results of the DN survey and individual DN written comments. Other sources included the research literature, letters received from district nurses in response to the survey, and from discussions with district nurses, colleagues and my supervisors. Themes emerged from the analysis of these sources, which were grouped under four main headings: bereavement follow-up, closure of relationships, personal and professional boundaries, and bereavement issues in general (see appendix 14).

6.3.2 Preparation for the interview

In qualitative research the interviewer is the main research tool and therefore how they present themselves to the interviewee is important. An extreme example was described by Sque (1997) who during one interview with a bereaved relatives of an organ donor, was told that the red colour of her clothes brought back upsetting memories of the blood on their daughter's clothes following her fatal road traffic accident. Although such examples are rare it provides a useful reminder to interviewers of their potential impact on the interview process. When interviewing district nurses I dressed smartly and described myself to all participants as a nurse (although not a DN) who was carrying out research at the University of Southampton. This was intended to try and create a professional commonality with shared experiences and interests. I felt that describing myself as a researcher may distance myself and make the interview more difficult, which is against the principles of semi-structured interviewing where the aim is to develop a rapport with the interviewee (Smith, 1995).

6.3.3 Informed consent and confidentiality

Prior to each interview, the participants were made aware of the nature of the research and that the data would remain confidential. However, I informed each participant that the audio-tape would be transcribed by a third person and may be read by both supervisors in addition to myself. All participants gave signed consent to be audio-taped during the interview and to the conditions of the study (see appendix 15). All but one DN was interviewed at their usual place of work.

6.3.4 Interview process

The length of time of the interviews ranged between 15 and 51 minutes (the average time was 30 minutes). Each interview continued until the respondent had covered all the areas of the schedule and each had been explored in depth. At the end of the interview the respondent was asked if there was anything else they wished to discuss and if so, they were allowed the opportunity to discuss this at length. All participants were offered the opportunity to verify what they had said by receiving a copy of the transcript. None wished to receive copy, although most were keen to receive a copy of any published paper.

During the interview process my epistemological perspective with the DNs was in contrast with that used in the collection of the data in the other studies. Rather than assuming an objective role, I specifically interacted with the DNs to question, explore, and elaborate on ideas brought up by the questions. The taped narrative is a construction of that interaction but aims to emphasise the individuality of the nurse's experience of bereavement support. From an ontological perspective I accepted the subjective nature of each nurse's experiences and beliefs, but hoped that the accounts captured the essence of their practice and beliefs. Critical feedback on my interview style and procedure was provided by one of my supervisors (SP). This was based on the first four interview transcripts. This was discussed at length during supervision and I endeavoured to modify and improve further interviews based on my supervisor's suggestions.

6.4 Data transcription

For the purposes of this research a verbatim transcription was required. All interviews were transcribed and the anonymised transcripts were transferred onto computer and stored according to the rules of the University of Southampton's data protection registration. All audio-tapes were stored in a locked cabinet. I transcribed the first three interviews myself so that I would be familiar with the procedure and its limitations. The remaining interviews were transcribed by two departmental secretaries. To promote a standard quality of the transcripts I described in detail the study to each secretary, and provided them with a copy of the interview schedule so that they could follow the questions and context of the interview. Each was also instructed to type a verbatim transcription including repetitions of words and all hm's and ah's etc, and to leave any words they were unsure about. Speakers were to be identified in the left hand column and a new paragraph used when the speaker changed. The transcriptions were saved to disc as a Microsoft Word document, and also printed off when verified by myself. Space was left in the right hand of the page to enable written comments when analysing the data.

6.5 Transcript reliability

The reliability of a transcript can be ascertained by having two people transcribe the same interview and then comparing the text. This method was cost prohibitive as I only had enough funds to pay for transcription once. However, when each transcription was returned I listened to the entire interview and compared the reliability of speech to the text. Any text that did not correspond to the actual speech was corrected, as were any spelling mistakes. When the speech was obscured this was noted in brackets in the text.

6.6 Transcript validity

Ascertaining the validity of an interview transcript is more difficult than ascertaining the reliability as transcription involves decontextualising and detemporalising spoken language from an interview context to a static written textual format, with each having different rules. An interview is a dynamic process with body language also being an integral part in that interaction. I nodded and smiled and encouraged the interviewee and such interaction is lost in any transcription. However, the transcript was a verbatim record of the interview and as such is a valid record of the interview process.

Any text derived from an audio-taped interview is an approximation of the actual interview and by necessity involves a series of judgements and decisions. It is essentially a social construction, which approximates the reality of the lived interview, but cannot be described as an 'objective' recording of that interview. In addressing this issue, Kvale (1996) suggests that there is no true, objective transformation from the oral to the written mode and that researchers should focus on obtaining the transcription most useful for their research purposes. In that broad sense a transcript can be described as a record of a performance (O'Connell and Kowel, 1995). In this research I was interested only in ascertaining the meanings and ideas expressed by each participant based on the verbal elements of the interview, which would allow me to develop themes. I was not interested in analysing the interviewee's tone of voice (prosodics), length of pause or paralinguistic expressions such as laughing, or gestures (extralinguistics) (O'Connell and Kowel, 1995).

6.7 Analysis of the data

The interviews were analysed using framework analysis (Ritchie and Spencer, 1994). Framework analysis was developed in the context of conducting applied qualitative social policy research and is a versatile method of analysis, which can be applied across a variety of qualitative research. Framework analysis provides a useful structure to the analytic process which includes five key stages: familiarisation with the data, the identification of a thematic framework, the application of a systematic index developed from the thematic framework to the data, charting the data, and mapping and interpreting the data set as a whole.

6.7.1 Familiarisation

While the data were still being collected I read through the early transcripts and developed ideas about the themes that were emerging. As more transcripts became available I immersed myself in the data by reading and listening to the taped interviews and also repeatedly reading each transcript of the interviews to identify meaningful categories in the data. As I read each transcript I made notes on the printed copies and developed ideas about themes. One method I used was mind-mapping (Buzan and Buzan, 2000) which involved drawing maps of linked themes from this study and integrating the results of the postal survey on one piece of paper. This promoted a creative development of the thematic relationships and generated new ideas. The diagrammatic illustration of the relationship theme (Figure 6.1) developed from such a mind-mapping exercise.

6.7.2 Identifying the thematic framework

The thematic framework is used to index the transcripts and was developed from the interview schedule, analyses of themes arising from the data, and the aims of the study. These initial themes were listed and updated throughout the analysis and consisted of a list of key theme headings many with sub-heading. I used this preliminary framework as a point of reference when I read each new transcript and at this stage I started to make conceptual links between the categories. The initial themes were used to code some of the data and further develop the coding framework. The data were returned to on several occasions to refine and define the evolving themes further. When all the transcripts had been read through at least once I had identified a total of 21 key themes, which were finally reduced to nine broad themes with subheadings. At this point I felt I had reached saturation for possible themes as all the text could be coded into one of the listed themes. This list was the basis of the thematic framework and subsequent index. A copy of the nine theme index can be seen in appendix 16.

6.7.3 Indexing

Using the final index outlined above I re-read every transcript and labelled the occurrence of a theme in the text by writing the corresponding thematic index number in the right hand side of the transcript. I also created an electronic version in Microsoft (MS) Word which allowed me to search each transcript using the '*find*' facility to identify the occurrence of any thematic index number anywhere in the transcript.

6.7.4 Charting

Charting continues the process of data analysis when all the transcripts have been indexed. When charting, the researcher identifies data relevant to each theme across all the transcriptions and 'lifts' them from their original context and rearranges them according to the themes. The way charts are designed depends on whether the researcher uses a thematic or case approach. If the analysis is by theme then the chart will represent a theme across all respondents; however if the analysis is by case then the chart will represent a respondent across all themes. I used analysis by theme, however, as I became increasingly familiar with the data during the process of charting, I started to form conceptual links between the nine themes and to look for broader themes that would link them together. I performed the charting stage of the data analysis in three steps.
(1) For each transcript I identified the occurrence of every thematic index code and copied each section of text corresponding to that index and pasted it into a corresponding new theme file. For each section copied I identified the DN and the page number of the transcript. This enabled me to locate exactly where I had obtained the data. This was repeated for each of the nine themes. (2) When all occurrences of the index code had been copied from every transcript I printed off a copy of all the corresponding text for that theme. This was repeated for each theme, until all nine files were printed. Each was read repeatedly to identify key headings for the chart and any associations between the themes. I also highlighted the best exemplars of each theme so that I could use them for quotations in the results section. (3) Finally, based on the analysis of the data I made a thematic chart (table) for each themes. This was presented with the sub-themes identified along the top and the DN down the left hand column. For each DN I copied the associated text from the participant's data into the appropriate heading. This produced a table of all the DNs data, grouped together for each themes, and sub-theme. An example of a chart for theme 4, support for district nurses is shown in appendix 17.

6.7.5 Mapping and interpreting

During the mapping and interpretation stage of data analysis, the researcher brings together the key characteristics of the data and starts to interpret the data as a whole. During the mapping stage I frequently returned to the four main research questions and attempted to address each of them in light of the findings. Qualitative data analysis is a dynamic and creative process requiring the researcher's immersion in the data, coupled with their synthesis of the findings in the data and academic and theoretical insights. Through this process I also explored new and emergent themes. This aspect of DNs work had received little attention; therefore this was an exploratory piece of research aimed at describing the range and nature of what DNs reported they did and to explain the reason for it.

6.7.6 Selecting examples of text for the results section.

During the process of charting I identified text that exemplified the key themes. Each exemplar was selected because it encapsulated and personified the theme and aided understanding by the reader.

6.7.7 Post interview letter

In May 2002 a letter with a brief questionnaire was sent to 21 of the original 22 nurses, asking them to provide free text comments on any changes that may have occurred following the interview (See appendix 18 for a copy of the letter and questionnaire). One nurse had moved and was unavailable. Of those contacted nineteen returned the questionnaire (90%), and two were contacted by phone call. Of the 19 who returned the questionnaire 10 wrote comments regarding the impact of the research on their practice, some of which are detailed in the discussion section in Chapter 7.

6.8 Findings

Nine themes were identified. A central broad theme was identified and labelled as 'relationships'. This expanded on theme 1, relationships with bereaved family and was associated with all the themes except interest, education and knowledge about bereavement (theme 7) and resources (theme 8). The nine themes are cross tabulated in Table 6.2, to indicate the associations between them.

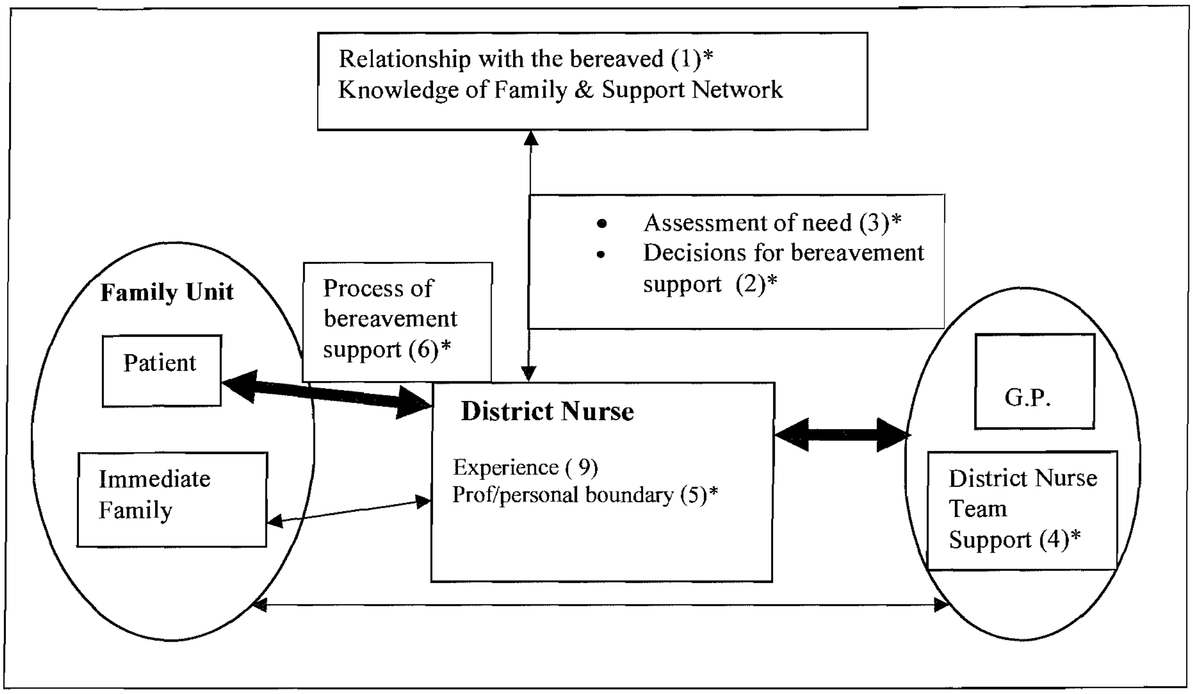
6.9 Theme 1: Relationships

Through the charting procedure a broader emergent theme termed 'Relationships' was identified which captured the importance of different relationships from the DN perspective. This theme had three key components central to bereavement support from the DN perspective, namely the relationship between the nurse and patient, between the nurse and bereaved person, and also between the nurse and their nursing colleagues. Relationships with the bereaved family was frequently associated with five other themes: influences on the decision for bereavement support (theme 2), assessment of needs (theme 3), personal and professional boundaries (theme 5), the process of bereavement support (theme 6), and personal stories and case example (theme 9). The concept of pre-death relationships with the deceased patient and the bereaved family influenced much of the DN practice in their bereavement support role. In addition, theme 4 (support for DNs), identified support from the DN team as the key source of support when carrying out potentially stressful bereavement visits. The essence of this was the relationship between the DN and their team and was therefore included under the broader theme of 'Relationship'. A conceptual framework of this interaction is shown in Figure 6.1 below. The arrows represent the directional flow of contact, information or support and the thicker the lines the stronger the potential link. In reality the link with the patient and bereaved people is variable in its strength, and is influenced by a number of factors including the needs of the family unit, the personalities of the family members and nurse, and professional practice of the nurse amongst others. A good relationship between the nurse and the bereaved person was perceived as essential to enable successful bereavement support. For most DNs it was a prerequisite to have developed a nurse-client relationship with the patient and the bereaved person prior to the patient's death. The changing nature of how DNs perceive bereaved people is another important aspect of bereavement support. When involved in the patient's care in the terminal stage of their illness, the family members are often perceived in a carer's role, but following the patient's death that role disappears and the relationship with the nurse changes. These issues are discussed more fully later in reporting the potential difficulties in maintaining a personal and professional boundary.

Table 6.2 The themes and conceptual links between the themes

	Relationship With bereaved family	**Influences on the decision for bereavement support**	**Assessment of needs**	**Support for District Nurses**	**Professional and personal boundaries**	**The process of bereavement support**	**Interest, education and knowledge about bereavement**	**Resources**	**Personal stories and case examples**
Relationship with bereaved family		Associated	Associated	Associated	Associated	Associated	Not associated	Not associated	Associated
Influences on the decision for bereavement support			Associated	Not associated	Associated	Associated	Associated	Associated	Associated
Assessment of needs				Not associated	Not associated	Associated	Associated	Associated	Associated
Support for District Nurses					Not associated	Not associated	Not associated	Not associated	Not associated
Professional and personal boundaries						Associated	Not associated	Not associated	Associated
The process of bereavement support							Associated	Associated	Associated
Interest, education and knowledge about bereavement								Not associated	Associated
Resources									Not associated
Personal stories and case examples									

Figure 6.1 **Relationship theme**



* Number refers to the number of the theme.

6.9.1 Pre-death relationship

Many nurses emphasised the importance of forming a relationship with the patient and family prior to the death. The results suggest that contact with the family was of key importance to the nurse in promoting a therapeutic relationship with the patient and also in building up a relationship with the family. Assessments of need and decisions about bereavement support were reported as being based on the nurse's knowledge of the family. Over time the nurse develops a knowledge base of information about the family unit, from which they are able to identify support needs. Knowing the deceased patient was important in forging a common bond with the bereaved. Through their care of the dying patient, the DN forges their relationship with the patient and their immediate family and support network. Throughout this stage other members of the primary care team will have some links with the patient and their family, particularly GPs and the DN's colleagues. Through contact with the family the relationship developed, which was important for later bereavement support.

> *"...... and the things that's the big influence there is how early we got the referral because it's no good somebody um off their legs needing a pump set up and then they ring us and say could you go and look after this person, we like to get in as early as we can. Even if we only visit once every so often, just to keep an eye on but we are building up a relationship with the family in that time, it's perhaps essential for when we are looking after someone and then again if we lose them" (DN 6 Page 2).*

Particular support or health needs may be documented by the nurse and shared with colleagues and the wider primary care team e.g. the GP. When the death was expected some DNs used the time during their palliative care to identify, pre-empt and work through personal issues before the patient died. This was seen as part of the care for the patient and the bereavement support for the relatives.

> *"....... we'd try and pre-empt any problems in bereavement by helping people um cope while the person is still alive and obviously a lot, a lot of the people we see, the death will be expected. Um we don't get heavily involved in unexpected deaths in our district-nursing role. So we have often been quite lucky in having time on our side um and by that it means that we have got time to actually talk through with relatives um and the patient themselves if it's appropriate, anything that's unresolved within their lives and perhaps any bad feeling that's going on between them. Um which we can help try and sort out before death".*
> *(DN 22, page 1)*

Overall most DNs provided bereavement support only to people who were close relatives of patients they had cared for in the community. The exception to this was when the GP had requested that they visit a bereaved person who they thought was vulnerable or not coping well. Only one DN (DN 3) said it was their practice policy to follow up all practice deaths with the offer of DN bereavement support. She reported how many of the GPs felt uncomfortable with bereavement issues and had welcomed her enthusiasm for developing a bereavement service as part of the DN role, which in effect removed the need for GPs to perform any bereavement visits.

> *".... I visit the whole practice, it's part of our practice protocol that the GP and I am always notified when someone dies and it's me that does the visit rather than the GP." (DN 3, page 3)*

In general most DNs did not deal with bereaved people who were unknown to them as they would not have been aware of their existence unless they were requested to visit by the GP. When there had been no prior contact with the bereaved person and the DN had not cared for the deceased as a patient it was reported that there was some difficulty in forming the sort of relationship needed for bereavement support to be successful. Contacts in such situations could arise when a GP had asked the DN to visit a bereaved patient, or when a DN colleague had been involved in the care of a patient but who was not available to visit when the patient died. The lack of relationship and background knowledge of the family was seen as embarrassing and uncomfortable.

> *"I don't think you can go into bereavement counselling cold, you have got to have known the patient and the carer and got some sort of family history".*
> *(DN 8, page 10)*

Conversely the lack of any prior relationship with the bereaved person was seen as a potential problem for some bereaved people. The potential problems of volunteers from bereavement groups trying to form relationships with recently bereaved people was highlighted by one nurse. This raises a number of issues about how bereavement visits should be carried out and by whom?

> *"I think it's important to people to know the people who are supporting them before the person died, sometimes there are people from CRUSE coming along to help but I wonder whether perhaps it would be better if they were known to the family before the death. Um people have said that to me that it wasn't very useful*

> *because they didn't know the person and they just couldn't relate to them and they didn't know their loved one." (DN 4 page 5)*

6.10 Theme 2: Influences on decision whether or not to support

The two main influences on nurses' decision making in bereavement support were intuition and empathy. Nurses reported many of their decisions were based on intuition, gained through prior knowledge of the family gained during their care of the deceased patient. This was closely linked with their assessments of needs. Several nurses described personal experiences (theme 9) that had influenced the way they carried out bereavement support. Through the experience they had developed empathy with bereaved patients.

> *"..... particularly if I get a cancer visit because my mother-in-law died of cancer. I find that very much you know whether if it was an awful RTA or something that would be different for me but I have more empathy with um the cancer patients"* (DN 2, Page 3)

Empathy was not always related to personal losses. One DN described the way she often cried with the bereaved person in an act of empathy through the sharing of a common loss. One DN reported how her sense of empathy which had developed from both her nursing experience and her experience of the death of her father was used to guide her decision making with bereaved people.

> *'I think empathy has got to be the main thing, I mean I have to say I don't have my own religious faith for me to go by I mean would respect that person if they may well have a religious reason but mine would be yes, very much empathy. Just try to think how you would be feeling in that (mumbled) situation, and also from experience to be honest. I think of um I used to work in Oncology before I came um on the district health, so death was a large part of the job to be honest and just, um personal experience as well I guess not just job experience. I mean having lost my dad, um...'*(DN 22, page 8)

Limited time was the main constraint to repeated visits for bereavement support. Speaking of her restrictions on time to visit one nurse reported:

> *"we might do weekly 'phone calls, reports or if the person specifically asks ah then we kind of just go by the needs of the patient, but it is a luxury I am afraid that can't always be umm followed up because of our time constrictions."*
> (DN 12, page 3)

Some DNs acknowledged the dilemma of wanting to carry out bereavement visits but being unable to do so due to lack of time. The visit was reported as being part of the nursing role and for some being unable to visit left them feeling guilty.

> *'........I feel really guilty if I haven't had time to go, and it's nice to feel that you did go, they are pleased to see you and you can come away feeling that it helps them, I mean that is what nursing is isn't it?'*
> DN 6 (page 3)

The distance that DNs were required to travel to carry out a bereavement visit was a factor mentioned by one nurse in rural West Dorset. Some visits would be missed or simply avoided due to the necessity of seeing patients on her caseload.

> *'Because we are quite a rural practice as well we have got 60 square miles so we have to plan our route, and umm you know it just depend on where that patient lived...so forth, and obviously you would have to do your essential visits first.'*
> DN11 (page 2)

6.11 Theme 3: Assessments of needs

Prior involvement with the care of the patient and their family was seen as the best opportunity for the DN to prepare the family for the imminent death and to have an insight into the needs of the bereaved people. Knowledge of the family support and social networks was also seen as important in aiding the DNs assessment of the needs of bereaved people, immediately following the death.

> *"... the majority of people that we go to, we have actually as district nurses looked after them, so we've become fairly involved sometimes in their families and know their sons and their daughters and the brothers and the sisters and that sort of thing and so you already know what family network they've got from looking after them before, particularly those that have got cancer and you have looked after for a while. You can gauge a little bit how much support they are going to have afterwards." (DN 3 page 4)*

Most DNs reported that they did not use any guidelines or assessments to assess patients and decisions for bereavement support which was frequently based on 'intuition'. guided by the nurse's prior knowledge of the family and their perceived needs. This provided a standard against which to assess the bereaved person's ability to cope and monitor any changes in health. Occasionally, when a GP had requested a visit to a bereaved patient the DN would use the basic DN assessment of needs to identify potential problems.

> *"I think it's just intuition it's not from national guidelines, it's um it's from your relationship with the person and what comes out on the day, you are led by the person and the people involved, and I think that's all you can do really, you can't, there are no rules are there when you, you're dealing with people who are bereaved I think you have to just go with the flow and and play it by ear." (DN 4, page 2)*

For those DNs who actively carried out bereavement visits the decision to stop visiting was mainly based on intuition or the observation that people were 'coping' or 'getting out and socialising again'.

> *J: When it comes to the time that you would like to sort of withdraw contacts with bereaved person*
> *DN: Umm*

> *J How do you go about that? and what sort of signs do you look for?*
> *DN: That they are doing the normal social things again, you know they are getting out and doing shopping or they are actually going out with family or they aren't tearful as soon as you appear, because sometimes you are just that reminder'*
> (DN 9, page 5)

Several DNs felt that the nurse could also be a painful reminder of the suffering of the deceased person, if the DN had been involved with the palliative care of the patient at home. In that situation bereavement visits were reported as a hindrance to the bereaved persons getting on with their life.

> *'J What sort of things would guide you in assessing to do a second visit?*
> *A I think it would be personally from them if they wanted us to go I do feel that quite often we are a reminder especially if you have been involved in a terminal illness at home, I find that we are not always a pleasant reminder of things so I very rarely do a sort of second visit, if I felt they wanted to go again'* DN 17 page 2

One DN suggested the importance of an impromptu visit to see the bereaved person. This was a means of assessing how they were coping with their normal daily life, rather than getting prepared for the DN visit. The DN emphasised both the social and physical signs that she would look for:

> *'I think generally how they are coping how their health is, material things, if they are eating well, they look good, they socialising, they are responding to your visits, they are ready to talk. I think there are physical signs that you look for to see if they are coping. Especially if you do an impromptu visit, then they are not prepared they haven't kind of put the kettle on they haven't got dressed up for you, I think you can tell, well maybe you can tell by their physical appearance, whether they have lost weight, or whether they are um going out and seeing their family how much they (car noise in background) how much neighbours pop in um depending on how their lifestyle'*. (DN 12, page 4)

Some DNs carried out a structured visiting pattern over time, but for many, lack of time and resources was a deciding factor in stopping the visits. One DN emphasised the importance of the patient's on her caseload rather than the bereaved who were associated with the deceased patient and therefore not part of her 'living' caseload:

> *'Well to be quite honest, we don't carry on indefinitely because I mean we are too busy, I mean if you spent all your time running round doing that you would never get to look after the living (sic)'* DN 20 page 3

Most DNs acknowledged limitations in their knowledge or their lack of skills and training in bereavement support and felt their main contribution was more as practical supporters and not as counsellors. As one DN stated:

> *'But I wouldn't in any term count myself a counsellor. I'm really am just a supporter and as soon as I sort of feel that someone is more complicated than I can deal with I just refer them on. But as I say because I know and until recently it's been very long before they would get an appointment, that I would try and give some encouragement along the way' (*DN3, page 9)

In general DNs reported that they would refer to other sources of help if they felt they had reached the limits of their expertise, or there was a particular health problem. This was generally when there was a mental health problem such as depression, where the DN felt that other professional help was needed. This was usually the GP in the first instance, but occasionally other colleagues such as the community psychiatric nurse. However, some DNs used other expertise as a resources and had developed a multi-agency approach to bereavement support. These DNs had not only considered the emotional aspects of bereavement but had assessed wider issues including practical support and financial advice from other statutory or voluntary agencies (e.g. the citizen's advice bureau).

> *"But we have also got a very good umm Citizens Advice Bureau umm (named person) who is attached to the surgery who is accessible and will visit people at home and umm I can certainly point the relatives to her or ask her to visit if that was an issue."* (DN 15, Pages 4-5).

One DN described how she and her colleagues in the surgery had instigated an arrangement with one of the assessors at the local Department of Social Security (DSS), who would visit bereaved people at their home and offer advice about financial matters to bereaved people who were often not used to dealing with their finances, it being the domain of the deceased person.

6.12 Theme 4: Support for DNs

When asked where the DN gained support when dealing with bereavement all but one described the importance of their DN colleagues and she described her main source as being her family. In addition the family and particularly husbands were seen as another source of support for all the DNs. Having a close relationship with the DN team was an important source of emotional support particularly when the death of a patient had been upsetting or traumatic. Nurses deal with many difficult emotional situations as part of their job, but when dealing with the death of a patient at home there is a shared experiential bond between the bereaved and the DN. This was perceived to be qualitatively different to the death of patients admitted to hospital where there is a shift of power and control away from the patient to the nurse and medical staff. When in a patient's home the DN is a guest and the patient and family have much more control and power. The DN team provides a closed professional forum for the sharing of these emotional issues, which appears to help the DN deal with the bereaved person in a professional manner. The data indicate that the team provides a safety zone.

> *"We've got a fairly good team and it's that's the crucial thing I think there is five of us, four of us are part time and one of us is full time. Um, and we meet every lunch time and we talk about you know, all the patients and discuss if we feel there are some particular area or if we feel we are not the right person with*

> *somebody, which does quite often happen, you know some people you just click with better than others, um then we decide who best to go in and see that person through." (DN 22 pages 9-10)*

The importance of DNs gaining support was emphasised by one DN who outlined how she found the bereavement visits mentally draining.

> *".....I am very lucky I have got a very good team here, I think individual support for the professionals when they are providing bereavement support has got to be very very strong because it can be incredibly draining you go home from it and can be absolutely exhausted, and you think, I have only been there for two hours and talked, but mentally it can be a very very big drain umm so as long as the support networks are in place for the rest of the professionals doing that support for the families umm" (DN 13, pages 13-14)*

All the nurses were entitled to clinical supervision, which usually occurred every six months. However, it was not seen as an appropriate forum in which to discuss bereavement issues or difficulties faced by the DNs. The immediacy of problems meant that by the time clinical supervision had been arranged it was too late to tackle the problem.

> *"Um it never comes up at the right time, if you've got somebody terminal like that you haven't got the time to make the appointment for clinical supervision and by the time it does come round you have dealt with it." (DN 6, page 5).*

Communication within the DN team was seen as the primary forum for sorting out any problems or issues rather than the clinical supervision session. The shared experiences of bereavement and commonality of working in the same community helped to foster a supportive network, within the team.

6.13 Theme 5: Maintaining professional boundaries

How a DN conceives of a bereaved person defines how they deal with them. When caring for the patient prior to death the key professional link is between the DN and the patient, with the family network an integrated part of that support. Over time, through regular visits and the increasing familiarity of the district nurse, a stronger relationship develops with the patient and their family. This can have a negative impact as well, as it can foster a sense of dependency from the family's perspective. However, when the patient dies the nurses' main professional link with the family is also terminated. The continued contact between the district nurse and the bereaved people in the patients' family network is dependent upon a number of factors including the conceptual framework of the DN, the perceived support needs of those bereaved and the strength of the pre-bereavement relationship with members of the family. Becoming emotionally attached to certain patients was also an aspect for some DNs, particularly when they had cared for them over a long period of time. Some reported that through the relationship they felt they had become almost a part of the patient's family.

> *"...it would be very easy with some of the relatives it is not even in a bereavement capacity because you almost become part of the family, it is very easy to almost feel like you want to keep going in to see them, even if it is just to pop in for a coffee because you feel like that you have been so much part of their lives for so long that they often feel a sense of loss if you're not going in anymore" (DN 10, pages 15-16)*

The maintenance of role boundaries was another theme closely linked with relationships. For most nurses bereavement visits lacked structure with most decisions about needs being based on intuition, and dependent upon prior knowledge of the bereaved person. The process of how bereavement support was carried out was also affected by the DNs perceived personal boundary. A lack of structure to the visits promoted the concept of a 'cup of tea and chat' type of bereavement support and appeared to confuse the role boundaries between professional and friend.

> *". they are not patients, they never were and it's something you've shared such an experience with them in their home that you just couldn't you can't be professional I don't think it's possible, there's a certain, there's a nurse patient relationship there but the predominating relationship is friendship" (DN 6 page7)*

One DN described how when strong relationships have developed over time, particularly through the shared experience of the death and bereavement, decisions about visiting could sometimes be based on the 'need' of the DN to see the bereaved person again.

> *".... if you are visiting somebody over long periods there is certainly some people that you do build up a stronger relationship with another which is a fact of life I guess anyway............and if you have brought, and if you have had that stronger relationship you personally have the need to go back, let alone what the patients' needs or the carers' needs are." (DN 15, page 3)*

DNs differed in the importance they attached to maintaining personal-professional boundaries. For some there was no pre-set view and the strength of relationship with the bereaved person was the deciding factor in how much they became involved in a more personal way. However for others there was a clear professional boundary which was not at question. They believed that the DNs had a professional role, which involved a certain emotional distance and detachment from the trauma and also the bereaved person.

> *"Um, I think it would be unhealthy um for the patients for us to get too involved because I think for most people we went in at a point in their lives which was extremely traumatic, you know the, it's usually the terminal illness of their loved one at home and they will associate us forever more with the death of their loved one. So I feel that we have to, we have to keep ourselves in that role and not then get involved as you know a personal thing, I mean I don't get involved with any of our patients on a personal level and I, I wouldn't want to"*
> *(J) "So, you you, your relationship is always a professional one?"*

> *(DN) "Um it's professional but I hope it's more a warm um, it it's a fine line isn't it, but it's not a cold professional role at all. It's very much a a, it's you know 'hi just wondered how you are, what you have been doing', all this, 'how's the job doing', you know that sort of um, warmth. But with a degree of detachment." (DN 22, page 11)*

The nurse's uniform was considered to be of key importance in maintaining role boundaries. The symbolic importance of a uniform is an important aspect of many professional relationships and the data suggest that most of the DNs utilised the uniform as a clear demarcation of the professional and personal boundary. The clearest example of this was when attending the funeral of a patient on a day off where almost all would attend in uniform as a 'representative of the profession'. Some DNs reported that sometimes their attachment to the patient was so strong that they felt the need to 'let go' and 'say goodbye' after the patient had died. Attending the funeral was sometimes seen as an opportunity to reach closure and was often for the benefit of the nurse rather than just the bereaved family. Although sometimes perceived as a cliché, one DN described her need to 'let go' and also to have permission from the carer to 'move on'. From the district nurse perspective the sense of loss was greater when the relationship with the patient was stronger. In addition for the bereaved family there is the additional loss of the DN as a source of companionship and support which is sometimes described as a second bereavement. For the DN too there is the potential loss of the relationship with the family with whom they may have maintained contact with over many years.

6.14 Theme six: The process of bereavement visits.

This was quite a generic theme and a number of themes were associated with the process of bereavement visiting. Prior knowledge and relationship with the bereaved person was an underlying theme and also available time. The DNs interest and experience of bereavement was a factor in both the timing of the visits and the structure within the visits. DN 5 expressed great interested in bereavement support and used a structured approach to the bereavement session based on her training and knowledge of a model of bereavement described as the 'grief wheel', which she used to assess bereaved peoples stage of 'recovery'. She described how the lack of support following a personal loss had greatly influenced the way she carried out bereavement visits over time. The availability of resources particularly time and staff was a major influence on the timing of the visits and the number of visits. It was common to book a bereavement visit for the afternoon to avoid the busy mornings. DNs acknowledged the need for an uninterrupted session during the bereavement visit and would plan that beforehand. However, practicalities such as being on call and carrying bleeps still had to be accommodated. Part-time staff did bereavement visits less frequently due to their limited time. One DN described how it was practical to involve the whole team in palliative support so that any member of the team could carry out a bereavement visit, as all were known to the family:

> "..... *we are part-timers here umm and I try very hard to get all of my team involved so that they do know all of us I don't like to go in myself as it is quite a time consuming thing"*(DN 9, page 3)

One DN reflected on how previously they had only been allowed to carry out one bereavement visit which was allocated a specific code and documented onto computer. To get around this restriction DNs would allocate a generic 'support' code to enable bereavement visits to be continued when they deemed it necessary.

> *"you had to just do one bereavement visit, that's all you were allowed to do so you had to put it down as something else like support..."*(DN 9, page 3)

6.15 Theme seven: Interest, education and knowledge about bereavement

All DNs found it difficult to recall specific information from their pre-registration education in bereavement support. There was little evidence that pre-registration education about bereavement or grief had any lasting impact on current practice, other than instilling vague notions of bereavement being a process involving stages, which appeared to be the fundamental understanding voiced by all the DNs. However, one DN recalled the lasting impact of being with a DN and witnessing an actual bereavement visit when she was attached to the community nurses as part of their pre-registration nurse training. For most DNs post registration training or personal study in bereavement was their source of theoretical knowledge. DNs who pursued a particular course about bereavement generally did so out of personal interest, making them a selected group

> *"I remember that that one time with the district nurse that I went on as a student nurse was was really pungent and it really stuck with me her words and they just flowed and I just said to her how you know how did you learn so yeh I think that's good experience."*(DN1, page 18)

All nurses conceptualised grief as a process involving stages to recovery. This was either explicitly stated or outlined when prompted. The 'Grief Wheel' was described as a model of grief used by DNs 3, 5, and 14. DN 12 also made reference to a cycle of grief with seven stages, although she could not recall further details about it. The grief wheel was described as a model taught on a post registration update within the East Dorset Primary Care Trust. The three DNs described above used this conceptual model in the assessment and support of bereaved people.

> *"DN: Yes tend to use it as a model as a guide, tend in my mind when I'm visiting someone to think where are they, are they um you know sort of in shock, have they moved to sadness and maybe suicidal tendencies have they sort of gone through the anger, um sort of you know right the way round ....."*(DN 3, Page 8)

6.16 Theme eight: Resources

The theme of resources represented sources of support rather than the broader sense of resources such as time, money or equipment per se, and was not associated with the central theme of relationships. Resources were closely associated with three other themes: influences on the decisions for bereavement support (theme 2), the assessment of needs (theme 3), and the process of bereavement support (theme 6). The impact of changes in the family structure and community network were reported by one DN. She suggested that the transient nature of families limited the number of people with 'roots' in a particular area, combined with a modern individualistic and insular mentality limited the sense of community that once existed in the 1950's and 1960's. She suggested that the impact of these changes was to reduce the scope of potential support networks in the community, which had wider implications for health and bereavement support. She suggested that while in the past neighbourhood support could reduce the need for health service or social service intervention, modern society and its lack of support caused people to look for help from outside agencies such as health care:

> *"……my husband's grandmother was a superb person at going round an visiting lots of widows she alone had gone along to the Cruse and sort of I am going back you know in the fifties and sixties, but you haven't got any of those kind of people because they are all out to work and so I think we have missed quite a group of people sort of in the community and I suppose if health don't pick it up I don't I'm not sure who will"* (DN 12, page 3)

Although there were several reports of resources available to the patients in the community (and bereaved relatives) such as Macmillan nurses, or bereavement counsellors, these appeared to be disjointed. One DN reported the inequality in resources available for palliative support, with cancer patients receiving greater support than non-cancer patients due to greater funding available from the cancer charities. The inequality also continued for the 'non-cancer death' bereaved person who was not entitled to particular support services that were only available to 'cancer death' bereaved people.

6.17 Theme nine: Personal stories and case examples.

The ninth theme was a generic theme which captured the DNs use of personal stories and case examples to describe a particular situation or experience. Often the stories contributed to the emotional voice of the participant, an aspect of themselves which had a poignant impact on the interview. The stories were broadly of three types: personal stories about experiences or traumas that had shaped their views and practice on bereavement support, stories that related to relationships and friendships with patients and bereaved people, and stories about difficult situations in their nursing career that had left a lasting impact on the DN.

One DN described a death that had a major impact on her and how her lack of bereavement support had been the key driving force in her determination to support bereaved people.

> *"It's actually given me the motivation to to actually, support bereaved people because when I was actually bereaved ten years ago, I I um had nothing, I had no support for me at all. I therefore fell into complicated grief and had I been supported by somebody possibly I think it might, I always wanted a professional person to come out, it might have been my GP or health visitor, had they come out I think I might have got on the grief wheel a bit quicker than I did. Therefore, I spent years of being very depressed and I put that really by lack of support there was at the time"*
> (DN5, page 7)

Another DN described a patient who she has become very attached to. The pain of the impending loss emphasised the downside of developing a strong bond with a terminally ill patient, and emphasised her own vulnerability to experiencing grief at the loss. The raw emotional impact of death and the feeling of helplessness often experienced by nurses in difficult situations was described by one DN who described the impact of witnessing a dying child over 30 years previously:

> *"I can still think back to the first child I saw dying I was……distraught, because I felt so utterly helpless, yes these parents had lost everything it was the precious to them as it was their only child, and what could I do nothing, there was nothing I could do or say that would make their loss any better and you know I was 21 years old when this child died you know and what did I know"* (DN 14, page 18)

6.18 Discussion

The results will be discussed in detail in the discussion section (Chapter 7).

Chapter 7 General Discussion

This chapter will provide a general discussion of the three studies described in Chapters 4, 5 and 6 respectively. Each study will be discussed in sequence although where appropriate the findings will be integrated using the principles of triangulation. The results of the interviews and assessments of bereaved people, described in Chapter 4 were limited due to a number of difficulties experienced. In this chapter I will focus on those difficulties and make suggestions of how these might be addressed in future research. The interview with DNs (Chapter 6) was developed from the findings of the postal survey of DNs (Chapters 5) and therefore has many related issues that will be integrated. Drawing upon the findings of these two studies I will describe the role of the DN in bereavement support as reported by the DNs surveyed and interviewed. Finally, based upon the findings of all three studies I will identify areas for future research and provide recommendations for practice when dealing with bereaved people in the community.

7.1 Discussion of chapter 4: Interviews with and assessments of bereaved people.

The following section will outline the problems faced in this study. There are a number of issues that would need to be addressed in future studies, these include the underlying methodology of the study, the data collection procedures, recruitment, and the pathologising of grief within the medical model. These will be addressed and suggestions made for future research in bereavement. Upon reflection there appeared to be two broad yet pertinent issues that needed to be addressed. Firstly the feasibility of repeating this research using similar methodology in light of its failings, and secondly to reappraise the research question and consider an alternative methodology. These will be considered in turn.

7.1.1 Repeating the study

A repeat of this type of research would have to address two main problems, namely recruitment and data collection. The main problem faced in the study was the lack of recruitment within the limited time frame. On reflection I would suggest one centre was not enough and any repeat of this type of research would require a larger scale multi-centre approach, rather than a single PhD student. Overall the task appears too large for one person and based on the recruitment rate of 13 bereaved people within 16 months (October 1999 until January 2001), I estimate it would require six centres each recruiting at least one person per month to identify the required 65 bereaved people, within a 12 month period.

The small sample lacked any ethnic diversity which if larger would be open to criticisms of sample bias and lack of generalisability to a wider ethnically mixed population. Future research could also seek to diversify its sample by including inner city populations with a greater proportion of minority ethnic groups. However, as recruitment itself was problematic specifying an ethnic sampling frame would add to that recruitment burden and may be unrealistic.

An alternative method of recruitment would be to use a different source of bereaved people such as the Register of Births, Marriages and Deaths database. This raises a number of ethical issues which would need to be satisfied before being considered. Also access to bereaved people via palliative support services, such as the district nursing services or other Community Nurses (e.g. Macmillan Nurses) would be a viable option, which has been utilised previously (Lyttle, 2001)

Using GPs turned out to be very difficult. Only 15 (60%) of the 25 GPs approached were willing to participate which was less than anticipated. This may simply be a reflection of the GPs I contacted and GPs from other areas may have been keener to participate in the research. The majority of GPs who declined reported lack of time and resources as their main reason for declining. Some were participating in other research. As Southampton has a large teaching hospital there are a number of medical students who carry out research projects with local GPs each year, there were also a number of research projects at the university involving GPs in the area, some of which involved my department (primary medical care). So it is possible that some GPs in the Southampton area experienced 'research fatigue', and did not really have their heart in the project.

It is possible that some felt the sensitive topic of bereavement was not appropriate for the type of research and so were reluctant to impose on bereaved people's grief. There may also have been concerns about intruding and the potential risk of complaints being made. Although these issues cannot be substantiated based on the limited feedback from the GPs they are issues to be aware of in future research in this area.

Another issue was the small number of bereaved people recruited from the participating GPs, which does not seem to reflect the actual number of deaths reported by the Funeral Directors (FDs) in the same GP catchment areas. UK estimates suggest that each GP will have 1% of their patients die per year; therefore with a patient list of 2000 the average GP will have approximately 20 deaths per year (Harris and Kendrick, 1998). Of the 15 GPs recruited there should have been a total of approximately 300 deaths per year, many of which would have been married or with a partner. In theory finding bereaved people via GP's should not be a problem. However, there are a number of possibilities as to why this was not the case.

Although a number of the people referred into the study were outside the inclusion criteria (particularly when referred by FDs), most GPs may have adhered to the inclusion criteria. I discussed the problems of recruitment with one GP who said that he seldom saw deaths under the age of 80 at his practice as the area had a particularly healthy population. Such longevity would limit the number of available bereaved people as the criteria was for ages between 50 to 75 years old. This may have accounted for some of the difficulty. In addition some of the deaths in younger people may occur in hospital or hospice settings and therefore primary care services may not be aware.

Alternatively, GPs may not have been aware of the deaths or simply not wished to include the patient. For example a person widowed may not have shared the same practice as their spouse. Also partners may not have been known to the GP as there may not be records of partners in contrast to married people, particularly as their surname may be different, there would be nothing to connect them, unless the relationship was known to the GP. Some people may not have visited their GP after their loss because they did not see bereavement as a medical problem or illness and therefore had no reason to visit. In such situations GPs may not find out about the death until some time later if at all.

Some GPs may have failed to remember the research. I had made attempts to remind the GP and practice manager about the study through regular two weekly phone calls to the practice to enquire about recruitment. Identification of bereaved people for the study may not have been given high priority by some of the GPs. Given their workload pressures, they may not have had time to find and contact the bereaved people for the study. Also there is the possibility that many people approached declined to participate. Unfortunately, I had minimal details of those that refused, as few GPs kept any records although from telephone conversations with both the participating GP and practice managers, it seemed that few if any bereaved people were identified in the first place.

Recruitment via FDs appeared to be more promising, however all the recruitment came from just three of the five participating FDs. In ten months of recruitment (March 2000 to January 2001) a total of ten people were recruited from the three 'active' FDs. Because each had kept a brief anonymous demographic profile of those to whom they had sent the letters, it was possible to estimate the number of letters needed to be sent out to find a participant. There were some initial problems and misunderstandings on the part of the FDs with completing the information, but once that was clarified, useful data was obtained.

The profile of non-responding widows / widowers was similar to that of responders; nine were widows and eight were widowers, all but two were aged 50 to 79. I estimated that for every tenth letter sent out by the FDs, three bereaved people agreed to participate which amounted to about a third of bereaved people approached. Based on the power calculation of the number of bereaved people required for the study (65 people in each group) it is realistic to estimate about 200 bereaved people would need to be approached.

This is too many for just a handful of FDs and so for future studies a realistic solution might be to spread the recruitment load over about ten FDs in non-competitive catchments area each sending out 20 to 30 letters over a period of 12 months, which is approximately two per month.

7.1.2 The data collection procedures used

Any replications of the study would require a re-evaluation of the data collection methods and the questionnaires used. In the present study there was a wide range in the time following bereavement to the first interview range 1 month to 12 months (mean: 4.2 months; median 3 months), but this reflected the difficult nature of the recruitment. The choice of face-to-face administration of the questionnaires appeared a better option than posting the questionnaires. Most people became emotional at some point in the interview, and some cried. Being present allowed me to reassure the person and to clarify any questions that they found difficult. Posting the questionnaires would not have allowed that support. However, future studies might consider a shorter postal questionnaire comprising of a limited number of self competed questions, but the ethical issues would need to be closely evaluated. However, the CIS-R would not be appropriate for self completion as it is designed for use in an interview. An alternative might be to evaluate the feasibility of carrying out telephone interviews with bereaved people. The reliability of such data may be lower than face-to-face interviews, but this would need further evaluation where uncertainty could be explored.

Although the length of the interview varied, all lasted at least an hour and the longest was about two and half hours. No one complained that this was too long and due to the sensitive nature of the topic it was often appropriate to proceed through the questions slowly allowing the person time to reflect on the answer and at times to talk at length about the deceased person.

Only one person withdrew from the study (participant eight) which occurred during the initial interview. She appeared increasingly irritated and defensive about the questions from the SF-36 and said she did not understand the point of being repeatedly asked similar questions about her health. On the final question she decided that she wished to stop the interview, and withdraw her consent to participate in the study. No other person found any problems with the SF-36, although others had problems with the ITG which will be outlined below.

I will now evaluate the pros and cons of each assessment tool used in the study based on my experience of using them with bereaved people.

CIS-R.

The CIS-R is a valid and reliable assessment tool for measuring and diagnosing depression and anxiety in a primary care population. However, it could take up to 40 minutes to complete and the paper version was not always easy to follow. The self-completed computer version on lap-top may have been easier. Only the total scores were used in the analysis because the paper version does not lend itself easily to diagnosis using the ICD-10 (World Health Organisation, 1992), whereas the computer version does. Future studies using the CIS-R would be better to use the computer version and not the paper version. Using the lap top has several advantages including the fact that it can be self-administered and provides a calculation of the scores and a diagnosis. An acknowledged problem with the CIS-R is the validity, as it is valid for 18 to 65 year olds, although there is evidence that it can be used on people up to 75 years old, hence its use in this study. Future studies should re-consider alternative valid assessment tools to measure mental health problems across a wide age range, with particular reference to people older than 75 years.

SF 36:

The SF-36 was easy to complete and took about five minutes. However, one person (participant 8) found the questions irritating due to their repetitive nature and withdrew from the study before completion. I suspect her withdrawal reflected her misunderstanding of the nature of the research. From the post interview conversation it appeared she thought the interview was aimed at finding out about bereavement from her perspective and to record her suggestions about future bereavement support. Some of the issues raised by those interviewed are discussed later.

GEI

The GEI is lengthy and can take up to 30 minutes to administer. There are a number of problems with this assessment and future studies should consider its use carefully and assess the feasibility of using another measurement of grief valid to a UK population. The GEI is North American and uses some terminology that is both culturally insensitive and not particularly relevant to UK populations in the post cold war era. Some of the questions are too dated, and / or contain a double negative. For example statement 41 " I have never dreamed of the deceased as still being alive."

Some of the questions are dated in terms of medical treatments and may not measure relevant aspects of grief. For example statement 12 'I rarely take aspirins' was designed to enquire about analgesia consumption for aches and pains e.g. headaches. However, this caused some people confusion as aspirin is currently used as prescribed anticoagulant therapy in some people at risk of cardiovascular disease. With modern analgesics available it is seldom used for headaches or aches and pains.

Another question, which caused some comments, was statement 114 'I shudder at the thought of nuclear war'. This was clearly associated with the North American dread of nuclear war in the cold-war era. Since the development of the GEI in 1979 there has been a break up of the Soviet Union and reduction in the cold-war threat of a nuclear war. Other more pressing global fears had been fuelled by media reporting including AIDS, global warming, the threat of a meteorite striking the earth and bio-terrorism. These threats appeared more relevant to the participants than nuclear war.

ITG

Only eight participants completed the ITG as five found it uncomfortable or had difficulty with the questions. One bereaved man (participant 1) said the ITG made him feel uncomfortable, even guilty for not having the emotions outlined in the questions. It is difficult to know why it made people uncomfortable but as the concept of traumatic grief has been developed in North America the questionnaire may lack cultural sensitivity and be difficult to understand from a British perspective. Overall I would suggest careful consideration if this questionnaire were to be used again in a UK population.

While the CIS-R- and SF-36 are generic assessment tools and not focused onto bereavement per-se, the GEI and ITG may be perceived as pathologising grief. This is a contentious issue and may be offensive or stigmatising to bereaved people who regard their feelings of grief and loss as normal and not pathological.

SSQ

The participants tended to score highly on satisfaction resulting in a poor range of scores, because most stated that they had sufficient social support. Due to the clustering of the scores towards the satisfactory end of the scale and small numbers it was not possible to perform any meaningful statistical analysis. On reflection the short six-item version of the SSQ did not add anything to the study. There was also a lack of depth to the questionnaire. Perhaps if there had been a greater number of participants then the questionnaire may have been useful, as there may have been a wider range in the scores. Overall, I would suggest dropping it from future research in this area.

Helpfulness of primary care support

The results of this questionnaire were not reported here as there are not enough data to carry out a meaningful statistical analysis. In brief five participants received a visit from their GP which all rated as at least useful, although the low numbers prohibits reflection on a broad range of views. With larger numbers of participants I believe that a modified and very much reduced version of the questionnaire could be used in future research. This could be used to develop any primary care bereavement services, based on the users' perspective.

Questionnaires to GPs

Unfortunately I only had eight questionnaires completed by GPs and so analysis would add little to the findings. However, a much reduced questionnaire may provide useful information in any future study.

The questionnaire for funeral directors

Unfortunately due to the low numbers of bereaved people recruited into the study the FD questionnaire contributed little data to the study. However, it would be useful to monitor demographic details of people contacted via funeral directors to enable a comparison to be made between non-responders and responders, to evaluate potential response bias.

7.2 Changing the underlying methodology of the study

So far I have outlined the problems faced in the study and made suggestion for future research that would seek to replicate a similar study. This study aimed to explore the physical and mental health problems of bereaved people, so that primary care support could be targeted at those in need. It used a quantitative methodology, with the aim of generalising the findings to a wider population of bereaved people. However, this methodological approach has potential limitations and an alternative research perspective could also be considered to address those limitations.

The quantitative methodology used in this study may not capture the essence of what bereaved people need or want from the primary care services. The measures used in the current study are open to the criticism. Some may appear to medicalise grief, which may not be acceptable to some bereaved people. The fact that five participants did not complete the ITG, also suggests that certain questions about mental health to bereaved people may be challenging.

The literature supports the view that bereaved people have an increased risk of mortality and mental health problems particularly in the first six months following the death. An evaluation of this in a UK primary care population would provide a useful estimation of the problem to enable a more effective targeting of resources to those people. However, what appears to be missing in all the objective measurements of health in bereavement is the subjective 'voice' of those bereaved. This concern has been raised by Klass et al (1996) who argued that too much emphasis has been placed on quantitative research with measurements of grief, outside the social context of the death, which has failed to look at the meaning or impact of grief to those bereaved.

Bereavement is a sensitive topic and it might be pertinent to ask what bereaved people want or need when they are bereaved and how the primary care services can support them. There is a danger of paternalism where the provision of a service is based on the provider's opinion of what is required by the service user. Primary care services need to be patient-centred with effective communication between all professionals involved. User involvement in mental health and bereavement services would help shape a service that took into account individual differences and needs.

One way to re-dress this potential imbalance would be to utilise methodologies that could inform from the bereaved person's perspective. This could include qualitative methodologies (e.g. grounded theory, phenomenology, action research) which would seek to describe and understand meanings from the participant's perspective. Methodologies such as grounded theory can also be used to generate theories, which could be tested through quantitative research using an inductive-hypothetico-deductive circle. Not only would such methodologies enable the experiences and opinions of bereaved people to be reported but it may also act to empower this vulnerable group in shaping service development.

During the assessment interviews I heard numerous anecdotal stories about bereavement experiences, which enabled me to reflect on the research and to consider alternative or addition areas of research. Two of the participants reported a similar story (participants 6 and 8). Both had looked after their husbands with Alzheimer's disease, and had become friends through the local Alzheimer's disease society. Both independently reported that their Community Psychiatric Nurse, who they described as providing substantial support for at least 12 month, had no further contact with them following the death of their husbands. In fact neither person had received any contact whatsoever from the moment of their husbands death. Both commented how the sudden loss of contact had been quite an emotional blow to them as they had developed both a fondness and reliance on the nurse. Such stories have an important message both about the needs of the bereaved people and the sorts of support offered in the community. Future research could capture a wealth of information from bereaved people by focusing on the bereaved person and utilising interview methods within a qualitative methodology in the research process.

As I described in Chapter 5 it was while reflecting on the methodological issues described above that I decided to develop my doctoral research to focus attention on the involvement of the District Nurse in the provision of bereavement support in the community. These studies were described in Chapters 5 and 6 and discussed next.

7.3 Discussion of chapter 5: A postal survey of District Nurses

There has been little published to describe bereavement support from the DN perspective or to provide an evidence-based guide to practice. The postal survey of DNs in bereavement support was novel as nothing similar was identified in the literature. It therefore provides the first overview of bereavement support from the DN perspective. In contrast in recent years the professional role and responsibility of nursing has been expanded and the skill base extended. In the UK the Community Nurse is one of the key providers of palliative care (Audit Commission, 1999) and in a recent editorial Payne (2001) suggested that bereavement support had become a fundamental aspect of palliative care. A recent briefing paper (Sainsbury Centre for Mental Health, briefing 19; 2002) proposed that Community Nurses should receive training on the identification and management of bereaved people, which would be part of their training in palliative support. As this may be the way that the district nursing service could develop I will use this as a framework against which to apply the results of the research to highlight key areas that require addressing, namely the importance of palliative care, the identification of bereaved people, and the management of bereaved people.

When a DN is involved in palliative care in the community their main focus of care is to the patient, who forms the DN's 'case'. Although the family is included in the overall care package they are neither a patient nor case. When the patient (case) dies some DNs perceive their role to have finished, and some either have no time or inclination to maintain contact with the family in the form of bereavement support. Many who continue with bereavement support do so in addition to their patient case load, and many perceive it as providing social support.

With limited literature to provide a structure and rationalisation to bereavement support it was not surprising to find a great deal of variation in the practice and opinion of the nurses surveyed. Eleven nurses discussed variations in practice. A substantial proportion of the respondents also lacked knowledge of administrative procedures and available services at the general practice to which they were linked. Factors such as age of the nurse, educational achievement and district of employment had an important impact on practice although the reasons for this remain unclear and further investigation is warranted.

When district nurses had been involved with the care of the deceased prior to death, the large majority (95%) believed that bereavement follow-up visits were part of their professional role. Most would visit within the first week, but the length of contact varied greatly from two weeks to over 15 month. Monroe & Smith (1997) discussed the value of a single structured visit to bereaved people, however the results suggested this was not the practice of most DNs.

One of the roles of the district nurse is to promote health (Baly et al, 1987) including the provision of information about health problems and services available. Some have suggested that district nurses are ideally placed to offer bereavement support, advice and information especially when they have provided palliative care in the community (Koodiaroff, 1999; Costello, 1995; Monroe & Smith, 1997). However, the results do not support this in practice as nearly half said no information was provided to bereaved people about the emotional impact of grief and one in ten didn't know if it was or not.

However, the respondents reported they were more likely to provide information on the practical considerations of bereavement (53%) and the services available (64%). Information is available and there are currently a number of publications aimed at informing bereaved people including '*What to do after a death in England and Wales*' (DSS, 2000) and other publications (e.g. CRUSE; Royal College of Psychiatrists, 1998) which could provide a useful resource for bereaved people and DNs alike. However, up to a quarter of nurses were unaware of the availability of written information for bereaved people. The reasons for this warrant further investigation as it may reflect ignorance of the available information, a lack of interest in providing information or a perceived lack of need in this client group.

Self-referral support agencies such as CRUSE, or local bereavement support groups may benefit some people. Studies of palliative care bereavement services suggest that professional services and professionally supported volunteer and self-help services are capable of reducing bereaved peoples' use of GP services (Relf, 1997) and their risk of psychiatric and psychosomatic disorders resulting from bereavement (Relf, 1998). However, Parkes (1981) suggests that bereavement support services are best targeted at those who are assessed as high risk and unsupported or perceive their families as unsupportive. For those at risk the provision of support may help reduce the consumption of drugs, alcohol, and tobacco by reducing anxiety and tension. It is therefore important that district nurses identify and offer support to those at increased-risk. These results suggest that nurses do assess bereaved people during their post-bereavement visit, however, few used any assessment tools and therefore the extent, depth and objectivity of this assessment requires further exploration.

District nurse appear to be well placed during their bereavement visit to assess potential health problems and to refer 'at risk' clients to more specialised services (Baly et al, 1987; Costello, 1995). Some bereaved people may experience 'abnormal' grief reactions, and mental health problems, and the elderly especially may be at risk of undernutrition (Todorovic, 2001). The majority of the respondents reported that they assessed bereaved people for their general physical health, ability to cope alone, loneliness, depression, anxiety and sleep problems. However, mental health problems such as anxiety and depression were not assessed as frequently, and only around a third said they assessed suicidal thoughts. District nurses may feel less competent to assess mental health problems or be more reluctant to discuss such topics with bereaved people. In fact the risk of suicide following bereavement is small and those at increased risk usually have a history of mental health problems, and so the nurses' practice may be justified.

There are many sudden and unexpected deaths from accidents or in hospital where the family have had no contact with the PHCT and may not be offered any support. When there has been no previous contact with the family most of the district nurses reported were either against (38%) or unsure (43%) whether post bereavement visiting should be part of their role. This may reflect uncertainty of their usefulness due to the lack of an established prior relationship between the nurse and the bereaved person. There is some evidence that district nurses feel uncomfortable with 'cold bereavement visits' (Lyttle 2001, p 632). However, these bereaved people are also at an increased risk, particularly when the person is old or in poor health and the district nurse may be in a position to offer advice and support. This is a contentious proposition as the district nursing team is a time-pressured resource and additions to their service may be unwanted and unrealistic. The usefulness of such a service also needs to be fully explored before any recommendations could be made.

Many bereaved people see bereavement support as an important role of the GP (Levy and Balfour Sclare, 1976; Daniels, 1994; Main, 2000). However, nearly half of the nurses felt that bereavement care was not the role of the GP, although 58% felt bereavement was best dealt with by a health professional rather than the family, suggesting that district nurses do perceive bereavement to have implications for health rather than being purely a social issue. These views appear to reflect a 'medical' approach to grief, although it is unclear to what extent nurses would describe grief as a 'disease' (Engel, 1961) or medical problem requiring treatment. The professionalisation and medicalisation of bereavement is a contentious issue. Walter (1999) has suggested that as society becomes increasingly secularised, bereaved people who once turned to their families, community, and religious advisors for support are turning to health professionals, which have important implications for the primary care services.

In addition any expanded role of the DN must be carefully considered and debated by both nurses and the primary health care team. One of the striking findings in both DN studies was the diversity of practice and lack of clarity of any agreed role for the DN in bereavement support. In view of the fact that bereavement visits continue to be carried out there remains little to guide the nurse in why they should visit and what they should do when visiting. The results found that there were few guidelines or general practice protocols providing any structure for nurses (or the primary care team).

Another important issue is that of occupational stress for the district nurse involved in palliative care and bereavement support. Evans (2002) carried out a small scale study of the perceived occupational stress of 38 district nurses, using a 50-item questionnaire. When the stress scores were ranked, caring for critical / terminal ill patients was perceived to be the eighth most stressful work event. Provision of emotional support to patients during palliative care has been described in terms of emotional labour, which can have a cumulative impact on the DN. Developing skills to cope with this pressure is important for their well-being. Skilbeck and Payne (2003) carried out a literature review of emotional care and support for patients with advanced cancer in which they identify the complexities involved in developing an emotionally supportive relationship. Interactions between the nurse and the patient were identified as the key aspect of this support mechanism The importance of an established prior relationships between the DN and the bereaved person generally through their palliative care was discussed by 24 DNs in their comments.

The evidence suggests that district nurses are a comparatively stressed group of healthcare professionals and that palliative support is a significantly stressful task. Bereavement support is another potential role involving an investment of emotional support that may add further stress to an already overstretched service. In addition the professional relationship between the carer and the district nurse changes from the time of death. Loneliness is a problem for elderly people and there is a potential risk of fostering dependence on the nurse, and a sense of loss when the visits end.

In a qualitative study of both community nurses and bereaved older people, Lyttle (2001) reported that bereaved people often referred to their community nurse as a 'friend' or person with whom they had a special relationship. The nurse must therefore also deal with the emotional context of the situation since the 'demand for friendship' and role ambiguity have been reported to be major stressors for district nurses involved in palliative care in the community (Wilkes et al, 1998). The role ambiguity demonstrated in bereavement support reflects general feelings in the community nurse teams. Constant changes in the primary care services and the increased skill mix in the DN teams have contributed to a general feeling of uncertainty, increased stress and vulnerability (Hallett and Pateman, 2000; Evans, 2002). A recent publication, "District Nursing: The invisible workforce" (Low and Hesketh, 2002) identified a DN service reporting overwork, lack of appreciation and lack of resources. Expanding an overburdened DN service to include bereavement support could have serious repercussions for the workforce if not planned carefully.

In some situations making long-term follow-up visits to bereaved people may reflect the needs of the nurse in addition to that of the 'client'. Structured visits, debriefing, quality clinical supervision and access to counselling may be ways of reducing stress in district nurses to help maintain role boundaries and a sense of professionalism.

7.3.1 Post-bereavement visiting.

Several factors were associated with an increased likelihood of the nurse performing a post-bereavement visit including working full-time (which may simply be due to a lack of time for those working fewer hours), the district of employment, having a diploma or degree, having an interest in bereavement, and being older.

Harris and Kendrick (1998) found those practices with a special interest in palliative care were more likely to offer routine support after bereavement as were practices that kept death registers. The survey identified that being aware of a death register at the practice was associated with an increased likelihood of post-bereavement visiting, which may both be indicators of greater interest in bereavement by the nurse.

The logistic regression model identified three variables as the best predictors of visiting: older age of the nurse, district of employment and higher level of academic qualification. Examination of the odds ratios in Table 5.2 (Chapter 5) shows that the odds of a nurse aged 31-50 years visiting were over three times those of a nurse aged 20-30 years (95% CI, 1.15, 8.8) and those of a nurse aged 51 years and older nine times higher (95% CI., 2.6, 30.5). The odds of a nurse with a diploma or degree visiting were three times those of a nurse without (95% CI, 1.64, 5.2) suggesting educational achievement has an association with practice in the context of bereavement support. The odds of a nurse in district 10 carrying out a post bereavement visit were eight times those of a nurse in district one, although the 95% confidence intervals did include one (95% CI, 0.61, 118). By including one within the 95% confidence intervals there is the possibility that the true odds ratio is equal to district one and therefore the nurses are not at greater odds of carrying out a post bereavement visit. However, there was evidence that district 10 was unusual in comparison to the other areas. Further investigation of district 10 revealed that district nurses had close links with a hospice based within the area covered by the district services. The hospice had good educational facilities and a reputation for regular educational updates and study days, which the nurses were encouraged to attend. It seems reasonable to suggest that these differences may reflect the influence of the hospice on the ‘culture’ of these district nurses and the practices to which they were attached.

7.3.2 Training and education about bereavement.

These results suggest a need for further training and education in the area of bereavement, particularly at the pre-registration level as only 25% of nurses reported this as a source of education. The main sources were practical experience on the job, reading nursing literature, and post-registration training. However, less than half felt they had received sufficient training in dealing with newly bereaved patients. This concern was reiterated in the general comments by the DNs and reflected their perceived constraints on their role in bereavement support. Based on these findings one has to question whether most district nurses really have sufficient knowledge, appropriate training or necessary skills to deal with bereavement. Nurses with a particular interest in bereavement and increased tendency to visit felt they had received sufficient training. The direction of cause and effect is uncertain: nurses who believe they have been better informed may have more confidence in dealing with bereavement issues, or attendance at courses may arise from their interest in bereavement.

7.3.3 Nurses' interest in bereavement

The strong association between an interest in palliative care and an interest in bereavement probably indicates that most nurses believe bereavement support to be an essential part of palliative care. However, one in eight respondents who declared an interest in palliative care reported no interest in bereavement care. This has implications for training in palliative care and standards of care delivered to the patients and families of the terminally ill at home. A potential need for bereavement support was recently highlighted in a study, which found that bereaved carers of cancer patients who had died at home had a higher level of psychological distress than carers of people who had died elsewhere (Addington-Hall & Karlesen, 2000).

7.3.4 The general practice with which the nurse had links

Overall the results suggest that district nurses are not aware of all the activities of general practice with which they have links. One fifth had no knowledge of whether their practice kept a death register, and did not know if their practice provided a professional bereavement service (e.g. counsellor, psychologist). These findings show that some district nurses lack information about the relevant services available, which may reflect a lack of interest on their part, or poor communication within the general practice.

7.3.5 The impact of a significant bereavement on the DNs practice

Seventy two percent of DNs reported that they had experienced a bereavement of someone significant. The textual data revealed two main themes defining how the bereavement had influenced nursing practice, namely developing a sense of empathy and improving nursing skills.

From the predominance of the comments regarding empathy it appears that nurses who had experienced a personal bereavement felt able to empathise with their clients and deal with them more effectively. Empathy is commonly used but poorly understood concept that has received much attention in nursing literature (Wiseman 1996; White 1997; Price and Archbold ,1997; Kunyk & Olson 2001) although an agreed definition remains elusive. Kunyk & Olson (2001) in their discussion of empathy identify five conceptualizations of empathy: as a human trait, as a professional state, as a communication process, as caring, and as a special relationship. There is some debate about whether empathy can be taught. Hope-stone and Mills (2001) interviewed 14 nurses working in a London Cancer unit. When asked about the teaching of the concept of empathy 50% believed empathy could be taught as a communication skill, while 50% believed it to be intuitive and based on experience.

The literature suggests empathy is a major component of effective nursing when dealing with emotional issues, particularly palliative nursing and bereavement support. Those nurses who had experienced bereavement outlined the way that they had learned from that experience and used it to empathise with those bereaved. However, it raises important questions about the nature of empathy, and begs the question whether empathy for bereaved people can be taught to those who have never experienced a close personal loss. These questions require further investigation particularly within the area of pre-and post-registration training. Although personal loss was reported to improve empathy it was not associated with an increased likelihood of carrying out a bereavement visit. However, personal loss was one of the factors associated with DNs reporting having received sufficient training in dealing with bereaved people.

7.3.6 Constraints on DN visits to bereaved people

Two important constraints on the DN role in providing bereavement support identified in the DNs written responses were limited time and lack of appropriate skills and training to deal with bereavement issues. Unlike many of the practical nursing skills performed by the district nurse, which can be time-limited and carried out swiftly (e.g. assessing wounds and changing dressings), bereavement support often involves little structure and can range between a friendly chat to a counselling session.

The findings of this survey have important implications for the education and training of district nurses in palliative and bereavement care, particularly if an extended role for the district nurse in bereavement support is envisaged. The comments by DNs indicate their concern about having appropriate skills and training and the results indicate few nurses gained knowledge or training about bereavement from their pre-registration training. Also post registration training may be specific to those with an interest in bereavement.

An area of concern when acting in a counselling role is that of maintaining a professional boundary. Within structured counselling sessions carried out by specialised professionals such as Counsellors, Psychologists or Psychiatrists there are clear boundaries regarding the time allowed during the clinical session and the role of the professional. Lack of structure due to lack of training may result in a problem with time management during bereavement visits. Setting boundaries could enable bereavement visits to be regularly performed.

One must also question the suitability of district nurses in specialist bereavement support, and also whether it is appropriate for district nurses to invest their time and resources in bereavement support. Most nurses believe that when they have cared for the deceased, they have an important role in the support of bereaved people following the death. However, few district nurses wanted a role in supporting those bereaved by sudden death in the community, who had not had contact with the district nurse services. Any expansion of primary care services to include bereavement support to these clients could result in district nurses being involved. This is not something DNs appear to want and the results of the survey suggest that the views of the district nurse needs to be fully explored prior to any developments being implemented.

7.3.7 General criticisms of the postal survey

When there is a low response rate to a survey it is difficult to generalise the findings and there is the possibility that respondents are systematically different from non-respondents. A response rate of 62% is very reasonable although it still lacks the views of 38% of potential respondents. Unfortunately, there was no way to compare respondents with non-respondents and therefore the survey may not be generalisable to the wider DN population. Although there were only five male respondents, this probably reflects the gender distribution of district nurses.

Although one must treat the survey as reflecting the actual views of the nurses there is also the danger that respondents may try and please those conducting the survey by providing the answer they presume is the correct one, which will reduce the validity of the findings. Attempts were made to reduce this problem by using anonymous questionnaires. However, I acknowledge that self-reported data may not necessarily indicate the actual behaviour or beliefs held by district nurses. This is also true of the written comments which were treated as genuinely held beliefs and opinions of the nurses.

Postal questionnaires are effective at gaining large amounts of data but unfortunately do not provide as rich data as interviews can. Some depth was provided by the free text comments by district nurses which allowed qualitative analysis. The survey provided useful information about district nurses and their role in bereavement support, which up to now had remained unknown. However, the study raised many more questions and to gain a greater understanding of bereavement support from the district nurse perspective I decided to interview a sample of DNs to explore their experiences about bereavement, their attitudes towards bereavement support and their views about the role of district nurses in bereavement support in the community.

7.4 Discussion of Chapter 6: Interviews with district nurses

This section will provide a summary of the findings. These will be addressed in detail in relation to each of the initial four research questions. Finally, I will outline a number of general issues pertaining to the quality of this research. These issues are relevant to how the quality of this research should be judged and pertinent to the justification of the chosen methodology, analysis and findings. The research will be judged by the four methodological criteria of trustworthiness (Guba and Lincoln, 1989; Guba and Lincoln, 1994) and the five criteria of authenticity (Guba and Lincoln (1989; Erlandson et al, 1993).

7.4.1 The concept of relationship in DN practice

The concept of relationships appeared to capture the essence of the DN role in bereavement support. One of the key findings was the importance the DN assigned to the formation of a relationship with the patient and family prior to the death. This relationship was seen as essential in enabling the DN to build up a knowledge base of the current and future needs of the patient, and their family after the patient's death. The importance of developing this early supportive role through palliative care was emphasised by most nurses. The importance of the nurse-family relationship was highlighted in Chapter 4 by two bereaved participants who reported their sense of loss when their Community Psychiatric Nurses, who had nursed their spouses for the previous year, discontinued all contact after their death.

The formation of a relationship with a patient or client is a key part of the nursing process so it is not surprising that relationships were of central importance to nurses dealing with bereaved people. It was however interesting to find one practice which had set up a DN bereavement led service which made contact with all bereaved people at the practice, irrespective of prior palliative support. This had been developed by one DN with strong Christian beliefs which was reported as her primary motivating factor. This was the only DN led bereavement service that I identified.

The importance of the DN team was another key factor and the importance of the supportive relationship from the team was emphasised by all but one DN. Such support appears valuable for reducing the stressful aspects of DN work and in particular traumatic situations found in palliative care and bereavement (Field, 1989).

However, in their exploration of teams in palliative care Cox and James (In Press) suggest that while teamwork work can bring many positive aspects to health care delivery, there are a number of possible tensions in teamwork including the needs within the team, the needs of the organisation and the needs of the consumers. These can also be a cause of stress for individuals.

The National Council for Hospices and Specialist Palliative Care Services suggest that teamwork is of primary importance for specialist palliative care services (NCHSPCS, 1998). The DN team may be one of a number health care professionals involved in the palliative care of the patient and collaboration is central to the delivery of effective patient care. This is particularly evident with palliative care which may involve the DN working alongside a number of other professionals including Macmillan nurses, social workers, GPs, and voluntary agencies.

Palliative support and health care provision has seen the development of such interdisciplinary team working over time changing from the institutional based medical-led team to a more complex interrelated service (Cox and James, In press). It is therefore important that not only do DNs have an effective team but that they also work in a cooperative manner with other groups of professionals and their teams in the form of inter-professional team work.

Several DNs reported that involving the whole team or several members of the team in palliative support enabled the stress to be divided between DNs as each developed a relationship with the family and could take over from their colleagues when required. Several DNs acknowledged that some DNs developed better (and closer) relationships with the patient and family and often took over to become the key DN contact. This however, raises a number of issues. Forming relationships in the context of bereavement support can in some instances be problematic both for the DN and the bereaved person. There is the rare but potential danger of exploitation of vulnerable people who made become dependent on the support provided. Although evidence from bereaved people suggests that most are complementary of the DN support provided and do not perceive it as problematic (Pearce, 1996; Lyttle, 2001).

Bereavement management decisions appeared to be very much dependent upon the nurse. Nurses used intuition and empathy as the main guidelines for decision-making, and this will be discussed later in more depth. Personal experiences were frequently cited as having had a major impact on their empathic stance. Restrictions and limitations on the amount of bereavement support were mainly explained as being due to limited resources, and in particular limited time and staff. Some DNs however, suggested that they wanted to do more but were restricted due to these limitations, which left them feeling guilty.

The process of bereavement support was much influenced by the relationship that the DN had with the family and the knowledge of their support system. Limited resources and practical issues were considered when carrying out a bereavement visit. This included the timing of the visit, so that busy mornings were avoided and afternoons selected as the choice for enabling longer support sessions. Most bereavements visits lacked structure both in the timing of the visit and in the process of the visit. One DN (DN 3) described her structured visiting pattern over five key points in the year corresponding to times of perceived support need: firstly, within seven to ten days of the death, then within four to six weeks, at three months, at six months and on the anniversary of the death. This was similar to the visiting pattern suggested by (Koodiaroff, 1999). In addition she was the only DN to describe a structured bereavement session based on the 'grief wheel', which she used as a model for her bereavement sessions. Most DNs described the bereavement visit as more social support and the chance to have a chat over a cup of tea, than any specific counselling session.

This tension between a 'cup of tea and a chat' approach and the 'counselling session' is fundamental to two broad perceptions of support. The former could be classified as 'intuitive' support, while the latter as 'interventional' support. Intuitive support can be described as that support which the nurse feels is correct given their knowledge of the person and their situation. One advantage is that it is not prescriptive and rather based on the nurses relationship with the bereaved person, within their home environment. It is a process that lacks structure but one that normalises grief rather than medicalises it in the form of overt assessment for signs of illness. One disadvantage is that it relies on the nurse having a good relationship with the bereaved person, which may not always be so. In some situations the nurse may not have known the person for very long or they may not have a good relationship. In such situations sitting having a cup of tea and chat could be uncomfortable for both parties. However, the concept of intuition is a term often misused or misunderstood. Benner and Tanner (1987) suggest that intuition is a 'sixth sense' which expert nurses utilise in clinical decision making. The development of expertise and intuitive skills require clinical experience and practice, something that newly qualified nurses or DNs may not have. Another disadvantage of this concept of intuitive clinical decision making is that it will vary depending on who is making the judgement and is not standardised.

Bereavement counselling on the other hand suggests training, structure, and in some instances a certain degree of medicalisation of grief. Such counselling requires that the counsellor undergoes specific training to achieve a recognised professional qualification. It is highly specialised and beyond the scope of most DNs.
Requiring DNs to train at such depth would require time, money and a DN workforce with an interest in bereavement counselling. The evidence suggests most do not want that and do not perceive themselves as counsellors, rather as nurses and supporters. Any suggestion to train nurses to such a high level would be open to accusations of attempts to change the nature and priorities in the nursing role.

These broad themes will now be addressed in more depth in the following section as I address each of the four initial research questions.

7.4.2 How does the district nurse conceptualise their role and practice in bereavement support?

The results indicate that the majority of DNs perceive their primary role to be palliative support for patients, which is one of the key DN roles in the community. The support of bereaved people appears to be viewed as a secondary role, which some DNs found hard to justify in terms of their time and limited resources. In addition these two roles differ in the clarity of role and the availability of guidelines and structure for DNs. In palliative support there are clear nursing practices, which include a nurse- led assessment and care plan, and specific nursing policies and procedures for the administration of drugs for pain control, and the use of medical equipment. These guidelines are frequently evidence based. In contrast, bereavement support currently lacks a clear nursing role and structure. There are no guidelines about what to do or clarity about the role of the DN in bereavement support. In the literature review little evidence was found for bereavement support from which DNs could base their practice. Some DNs differentiated their 'supportive' role from that of a 'counselling' role and acknowledged their lack of appropriate skills in bereavement counselling, which was identified as a skill requiring specific training. There is evidence of a role boundary that most nurses perceive when dealing with bereavement. Nurse training does not equip the nurse to provide a bereavement counselling service. Further specific training and professional accreditation would be required to achieve this.

Broadly speaking there is a continuum in the way DNs conceptualise how they should contact bereaved people ranging from a proactive approach personified by DN 3 who made contact with all bereaved people in her general practice, to the other extreme were contact with bereaved people was limited to the collection of equipment. Most DNs appeared midway on the continuum and suggested a limited DN role in bereavement support. However, even DN 3 acknowledged her limitations in bereavement support, suggesting she had a supporting role rather than a counselling role. So it appears that certain aspects of bereavement support were not perceived as being the role of the DN.

In general most DNs had no clear concept of what their professional role should be in bereavement support, but there was ample evidence that most DNs believed bereavement support was a part of their role. Regardless of DNs views about the need for bereavement support in reality the process of bereavement visiting is influenced by intervening practical considerations such as lack of time, working practices (part-time or full-time), limited resources, and geographic boundaries. The lack of professional guidelines means much of the bereavement support role appears to be developed on an ad hoc individual nurse basis which develop as a result of the DNs personal views, experiences, intuition and empathy. There are two sides to this approach. Empathic understanding and listening to bereaved people may be a useful model for normalising the experience of grief. Other health professionals (e.g. GP) may use a medical model, with an emphasis on assessment of health and illness which might serve to 'psychologise' or medicalise the grief experience. The sharing of information with a nurse who listens without judgement may be perceived as a non-threatening and helpful experience for bereaved people, which on the face of it appears to be nothing more than a chat. However, not all nurses are equally skilled in empathic listening, and for those nurses a more structured and 'purposeful' visit may be best.

Personal experiences of bereavement were closely associated with a desire to develop bereavement support in their DN team. Of three nurses with a particular interest in bereavement support each was motivated by personal and not professional or evidence based guidelines. DN3 who had set up a DN led bereavement service which covered all bereaved people at the practice, described her primary driving force as being her deeply held Christian beliefs which had motivated her to develop the service. In contrast DN 5, and DN 16 who both had very strong views about the importance of bereavement support had formed their views based on their personal experiences of loss and the lack of available support. It appears therefore that most DNs conceptualise their role and practice in bereavement support based on their experience and personal beliefs rather than nursing guidelines, which demonstrates the subjective nature of bereavement support from the DN perspective.

DNs that carried out bereavement visits reported that these were helpful to the bereaved person. Apart from DN 5 who described her use of the grief wheel, there were no reports of structured assessments of progress being carried out on the bereaved person. How a DN ascertains that a person no longer required a visit appeared arbitrary and difficult to identify. Assessment of bereaved people appears to be carried out on an ad-hoc basis, and only reported if the DN identifies a medical problem. This also results in a limited documentation of the visit.

At present most DN visits are for social support although they may in some instances identify potential health problems, most may simply provide social support to vulnerable and lonely people. This raises the question of whether this is appropriate use of DNs limited time and resources or whether other support could be identified.

The concerns about bereavement support in the community were raised in a recent briefing paper published by the Sainsbury Centre for Mental Health, which suggested that The National Primary Care Mental Health Training Strategy should develop curricula that allow:

> *'District nurses to receive specific training on the identification and management of bereaved people as part of their training on the care of the dying'*
> (Sainsbury Centre for Mental Health, briefing 19; 2002: page 6)

Such implications raise the issue of an expanded role of the DN in bereavement support, although the data does not support this as being from the DN perspective. However, current developments in the guidelines for service delivery may necessitate the expanded role of the DN in both palliative support and bereavement support.

The National Institute of Clinical Excellence (NICE) has reviewed the evidence for palliative support for patients with cancer which included bereavement support for the carers and relatives. The latest draft guidelines (NICE, 2003) provides evidence to support a number of changes in the provision of bereavement support; one of which is that bereavement support should be an ongoing process starting at the terminal phase. This would take into consideration the concept of anticipatory grief which carers and relatives may experience. It also suggest that

"Accurate assessment measurement tools are needed which are currently lacking. These instruments should be generated directly based on the clinical judgment of staff." (NICE, 2003. p 337)

The authors go further and suggest that health professionals should consider what is selected as relevant for assessment. These should be relevant and matter to the bereaved relatives and should be measured using appropriate and sensitive outcomes measures. The examples provided of areas for assessment were social support, affect and loneliness, which it is suggested could be used to enable the matching of specific people to specific interventions. Another role would be the provision of information about bereavement, grief and a wide range of support agencies both statutory and voluntary.

Levy et al, (1992) examined the Parkes' risk index from which most other assessment tools are derived and reported that the instrument could not be relied upon as a predictor of outcome. However, it was found that nurses' judgment of a person's ability to cope was the most reliable. The results from a postal survey reported that the majority of assessments of risk and the need for bereavement follow-up in palliative care units was carried out by nurses. Few used the standardised measures to target support and most based their judgment on their experience (Payne & Relf, 1994). These authors also suggested that the training and support needs of nurses involved in any form of risk assessment must be recognised. This raises an important point because although the NICE guidance focuses specifically on cancer care there are wide ranging implications for nurses in their delivery of bereavement support to all bereaved people irrespective of the nature of the cause of death. DNs form part of the backbone of palliative care in the community and would be a key element in the implementation of these recommendations from NICE. The changes suggested would necessitate fundamental changes at pre and post-registration nurse training. All DNs would need to be far more aware of bereavement, grief and support agencies. Bereavement policies would need to be written and implemented. They would also be required to be competent in a wide range of assessment tools which may include those to assess mood (particularly depression and anxiety), and social support. In addition the bereavement services would need to be carefully coordinated across a variety of agencies involved in the palliative support, one of whom may be the DN, so that there was no omission of care or duplication from different groups.

Several authors have suggested that DNs could play a key role in bereavement support including assessing the needs of the bereaved person, helping them with the pain of grief, offering advice, support and information (Koodiaroff, 1999; Costello, 1995; Monroe and Smith, 1997). However, this view appears to be based on the anecdotal evidence of these authors or on limited small-scale studies (Koodiaroff, 1999). The concept of the 'management' of bereaved people is an area that needs further clarification. There is some evidence from the data to suggest that DNs who have developed a relationship with bereaved people through their palliative support may be best placed to provide information and support to bereaved people, and to identify particular problems which could be referred to specialists' services.

DN 15 outlined how she had developed her role as an information provider to bereaved people. This could be a potentially useful role for the DN services which could encompass information about contacts with local agencies in both the statutory and voluntary arena. It could be argued that DNs are only one support agent in a larger network. Others include social services, religious groups, the clergy, citizens advice bureau, and for some people DNs may not be important to them. By developing a network of contacts to refer bereaved people onto DNs could ensure that bereaved people are able to contact a variety of important services covering a wide range of issues, that could provide emotional, financial, and practical support. Cowley et al (2002) has suggested that the successful provision of palliative care is dependent upon effective interagency and inter-professional working. A similar argument can be made for bereavement support were the multiple needs of the bereaved person can not always be successfully dealt with by the DN. Therefore the DN may be best placed to identify the needs and refer to other agencies with the specific skills and expertise to address the need.

Based on the limited data of this study there is little evidence that the majority of DNs would wish to develop specialist bereavement skills themselves. However, there may be the potential to enable a change in the role for the DN in bereavement support. This is an area that needs to be analysed and discussed further.

7.4.3 What guides the district nurse in assessing bereaved people and providing support?

A key factor, which DNs reported they used to guide them in their assessment and support of bereaved people, was knowledge based on their relationship with the patient and their family while providing palliative care. The importance of the nurse-patient has been the topic of recent theoretical debate (Salvage, 1993; May 1990, 1991, 1992, 1994) and has been examined in research from the perspective of community nurses' in palliative care (Luker et al, 2000; Wright, 2002). Much of the research pertinent to this area has focused on nurse-patient communication (Melia, 1987; , Macleod Clarke, 1986; May, 1990) and the concept of 'knowing the patient' (Salvage, 1993).

The importance of 'knowing the patient' is seen as a fundamental component of the 'new nursing' movement (Salvage, 1993). The underpinning philosophy of the 'new nurse' rest on a basic assumption that both patient and nurse are equally keen to participate in the formation of a therapeutic bond. One issue is the change in the professional boundary of the nurse towards the patient. May (1994) suggests that patients who do not wish to collaborate in this type of nurse-patient relationship, may be labelled as non-compliant. Salvage suggests:

> *"The focus of the nurse-patient relationship does address an area of great importance to patients, but a desire to be treated with warmth, kindness, and sensitivity, does not necessarily mean all patients want close relationships of a quasi-psychotherapeutic kind"* (Salvage, 1993. p 18)

These contentions will be addressed in light of the DN findings. On a theoretical level it is useful to differentiate between knowing the patient and knowing about the patient. While the former implies a close-relationship that allows the nurse access to detailed personal information and the formation of a therapeutic bond, the latter could involve gathering superficial information about the patient's ability to cope, their knowledge of their illness, their lifestyle including their socio-cultural perspective and financial situation. All of which could be assessed using standard tools.

Melia (1987), studied the occupational socialisation of nurses in Scotland in the late 1970's and reported that task oriented nursing work developed as the norm through a process of occupational socialisation, in response to a number of pressures from the nursing staff and the hospital culture. While at the theoretical level talking to patients is emphasised as a precursor to developing a therapeutic relationship (knowing the patient), the practical realities were that talking to patients was not seen as 'real work' and therefore was frowned upon. Successful socialisation into the ward culture necessitated the limitation of nurse-patient interaction. Another important factor is that bereaved people are not the DN's patient and therefore the development of a DN-client relationship may be qualitatively different. This demonstrates the importance of contextualising such work, but highlights an important area that requires further research.

Much of the work to assess the nurse-patient relationship has come from sociological work based in hospital settings and not the community, so transferring these findings to the community setting could be difficult. One difference is the shift in the balance of power between nurse and patient in the hospital, where the patient is 'admitted' to an institution and expected to conform to a patient role. Conversely, the DN enters the patient's home to carry out a specific task and must adapt to the patients way of life. The balance of power is much more in favour of the patient within their own home.

Luker et al (2000) reported the results of interviews with 62 members of the DN team, which did include some non-qualified members (Nursing assistants). 'Getting to know' the patient and family was identified as an essential antecedent to the provision of high quality palliative care. The importance of early access to patients and effective communication was also identified as facilitating the formation of that key relationship. The importance of the relationship was also identified in a small study involving semi-structured interviews with six DNs, which identified the development of the relationship between the DN and the client (patient) and their family as a key aspect of palliative care in the community (Wright, 2002). Specifically knowing the bereaved person was a key factor in nursing decision-making and subsequent bereavement support.

Luker et al (2000) conceptualise the process of getting to know the patient and family as 'invisible work'. It is suggested that high quality care is grounded in the communications between the nurse and patient, and between the nurse and relatives. The length of time and continuity of care were also important to this process. Radwin (1996) explored the emerging concept of 'knowing the patient' as a factor in therapeutic decision making. Based on a review of the literature and her PhD thesis (Radwin, 1993, cited in Radwin 1996), she identified three factors repeatedly associated with knowing the patient: The nurses experience of caring for the patient, chronological time, and a sense of closeness between the patient and the nurse. These factors enabled the nurse to develop individualised care. Similarities can be found in my results, where DNs emphasised the importance of the shared knowledge and experience of the patient and families, coupled with the development of a 'relationship' between the DN and patient and the family.

There appears to be a conflict between the theoretically driven concept of the importance of 'knowing the patient' to enable the formation of a therapeutic relationship and the practical limitations of time and limited resources. In addition one must question the desire on the part of both patient and nurse to develop such a close therapeutic bond. There are three key areas that my research has identified in relation to these concepts, all of which need further clarification and research. Firstly, the key focus of the community work has been with patients in palliative care and not bereaved people. Bereaved people are not patients and therefore the relationship may be qualitatively different. Secondly, it may be difficult to transfer patient-nurse communication models derived from hospital settings to the community (home) setting. There is a subtle shift in nurse-patient power, and relationships may be different. Thirdly, the current drive by NICE to develop guidance and policies to deal with palliative care and bereavement support is thwart with difficulties. It may prove difficult for DNs to comply with the requirements of these guidelines due to competing demands and limited resources.

Luker and Kenrick (1992) carried out an exploratory study to identify influences on clinical decision making in a sample of 47 Community Nurses in the UK. It was found that although much of the Community Nurse work required scientific knowledge and situational context, one important source of influence was discussions with nursing colleagues. The importance of DN support was also identified in the findings. The importance of a close relationship with their DN colleagues enables a forum of discussion about bereavement issues, allowing decisions about support to be negotiated.

Other factors reported as important guides to bereavement support were empathy, intuition, and personal experience. Empathy, intuition and personal experience open up the discussion about how DNs develop knowledge about bereavement support. Carper (1978) suggests four patterns of knowledge in nursing practice: (1) empirics, the science of nursing; (2) aesthetics, the art of nursing,; (3) the component of personal knowledge in nursing; and (4) ethics, the component of moral knowledge in nursing. I will now apply Carper's model of knowing to the data to help illuminate some of the influences in the decision making process reported by the DNs.

Empirical knowledge utilises the positivist paradigm whereby knowledge is gained through systematic investigation, observation and testing. The data indicates that few nurses utilised research about bereavement or grief. Most DNs reported a vague notion of a stage or phase theory of bereavement, yet only one made specific reference to recent theories namely the dual process theory (Stroebe 1999). More recent post-modern theories which conceptualise the continuation and re-integration of the loss into everyday life, rather than a 'recovery' stage were not voiced (Klass et al, 1996; Walters, 1996).

Two nurses (DN 3, and DN 5) made explicit reference to their use of the 'grief wheel' as a model of bereavement, and both appeared familiar with some of the bereavement literature. Berragan (1998) suggests much empirical knowledge is difficult to apply to nursing practice as there may be some difficulty bridging the theory-practice gap. The impact of local study days which taught the 'grief wheel' appears to have promoted a useful means of providing theoretical input that some DNs have applied to practice.

DNs could recall little educational input from their pre-registration courses, this was backed up by the results from the survey, see Chapter 5 (Birtwistle et al, 2002). There is some evidence that bereavement is conceptualised and taught within the medical model. The effect is to instil into nurses the world view of grief being a series of stages aimed at detaching from the deceased person with an ultimate goal of recovery, rather than alternative models which suggest a continuing relationship with the deceased as suggested by others (Walters, 1996; Klass et al, 1996). This bias appears to have a major influence on how DNs conceptualise their role in bereavement support and is an area which needs to be redressed at pre- and post-registration education and training.

Ethical knowledge links the ethical and moral implications to life and professional practice. The strong religious beliefs outlined by DN3 perhaps personify the best case scenario of ethical 'knowledge' being applied to DN practice. DN3 expressed her deeply held Christian ethical principles as the main guideline to her professional practice with bereaved people. The importance of ethical issues is outlined by the Nursing and Midwifery Council code of professional practice (NMC, 2002), which provides a broad framework of how patients / clients should be treated within a nursing context. Respect for autonomy and the individual rights of the patient / client were issues that many DNs stated they used to guide their practice, by not being prescriptive.

Aesthetic knowledge identifies with the 'art of nursing' and involves characteristics of perception, understanding and empathy. This type of knowledge is suggested to enable the nurse to empathise with the life of a patient / client. Empathy as a guiding force in decision-making was reported by a number of nurses.

Empathy is a concept that has received much interest in the nursing literature (Morse, et al 1992; Price and Archibold, 1997; Wiseman (1996); White, 1997; Yegdich, 1999; Reynolds et al, 2000; Kunyk & Olson, 2001) yet its meaning still remains problematic. Empathy has been described as an important concept in the interpersonal repertoire of the nurse (White, 1997). Rogers defined empathy as:

'to sense the client's world as if it were your own, without ever losing the 'as if' quality' (Rogers, 1957: page 95).

Rogers describes empathy as having three components: affective (sensitivity), cognitive (observation and mental processing), and communicative (helpers response). Within nursing the emphasis appears to be on communication, which is seen as one aspect that can be taught and nurtured in practice. The fundamental aspect of empathy is the nurse-patient relationship, which was also central to the research findings. Any description of empathy is worth a cautionary note. Many recipients of professional help do not always feel their situation is understood, regardless of the how empathic the professionals believe they are (Reynolds et al, 2000). Some DNs reported using empathy based on their own personal experiences and thereby having a direct understanding of the bereaved persons situation. Others reported drawing upon their nursing experience to develop a sense of empathy with the bereaved person.

Carper's final pattern of knowing is described as personal knowledge. Personal knowledge includes the concept of intuition, knowing, experiential knowing, interpersonal knowing and reflective practice (Berragan, 1998).

The data identified one key aspect of decision making as being intuition which has frequently been associated with nurses' clinical decision making (King & Appleton, 1997; Hallett and Pateman 2000; King & Macleod Clarke, 2002). In one qualitative study of 62 Community Nurses, Hallet and Pateman (2000) reported clinical decisions made by Community Nurses in the area of wound care were largely intuitive, and yet closely related to diagnostic reasoning.

King and Appleton (1997) describe the attributes of intuition as being:
'the integration of forms of knowing in a sudden realisation. This then precipitates an analytical process which facilitates action in patient/client care' (King and Appleton, 1997: page 195).

The reflective process on decision making may also be influenced by the support and discussions which DNs have with their team. The practical restriction on bereavement support was acknowledged by most DNs. These included limited resources, time and lack of skills. In addition the impact of early hospital discharge particularly following surgical procedures has increased the work load of DNs. The limitation on resources is an area that needs careful examination should any expansion of the DNs role be considered.

7.4.4 What guides the district nurse when deciding to stop bereavement visits?

Decisions about stopping bereavement support were conceptually linked with the previous research question. DNs reported knowledge of the pre-bereavement relationship as an important aspect in the assessment process. Intuitive decisions were also aspects in deciding that the bereaved person was able to cope. Coping included ideas about getting on with their life, going out and socialising, without being as emotional about the death.

The concept of coping was very much based on the DNs assessment of the person particularly their eating, sleeping, mood and social life. This appears to reflect the medical model of grief being a series of stages to recovery. The lack of time and resources was frequently identified as a major factor in deciding to stop. One DN (20) emphasised the importance of the patients on her caseload rather than the bereaved who were not perceived as part of that load.

This raises a number of important questions about the medicalisation of grief and how DNs perceive bereavement within the medical framework.

When asked about their theoretical stance on bereavement and grief all the DNs interviewed described grief vaguely in terms of a stage or phase theory. The two theories mentioned explicitly were the stages of dying (Kubler-Ross) and the Grief wheel. The latter was taught by a East Dorset based Psychologist on an in-house bereavement workshop organised by the local Community Trust. This raises interesting questions about the teaching of bereavement and grief at both the pre-registration (undergraduate) and post-registration (post-graduate) level.

7.4.5 How do district nurses maintain their professional and personal boundaries when dealing with bereaved people?

The essential finding to this research question was that not all DNs maintained a professional boundary. Some DNs described how the relationship developed over time had made them feel a part of the patient's family. When the patient had died strong emotional attachments with the bereaved person could predominate the nurse relationship, resulting in the formation of a friendship rather than a professional relationship. The concept of a friendship between DN and bereaved person was also reported by Lyttle (2001), who found that bereaved people often referred to their community nurse as a 'friend' or person with whom they had a special relationship.

However, again there was a range of reported views on the importance of maintaining a professional boundary from the distant professional to the friend. The blurring of the professional boundary between nurse and person could have negative effect on the bereaved person through increased dependency. However, there are conflicting pressures on the DN. On the one side they are expected as part of their role to develop a close relationship with patients and their family during palliative care and yet to maintain a professional distance. In addition there is the ever danger of a potential breach of the Nursing and Midwifery Council (NMC) code of professional conduct (NMC, 2002)

This raises important ethical and professional issues as the concept of 'friendship' is somewhat different to the concept of 'patient or client'. In the latter any nurse-client dyadic relationship implies a power differential with the nurse exerting both professional and expertise power over the client. However, if the relationship is blurred into a friend-client this opens the possibility of abuse of power. Yet the power differential is somewhat different when dealing with patients, clients and bereaved people within their own homes.

The influence of the DN uniform was found to be an important way in which DNs maintained their professional boundary. There are many elements to the contemporary nursing uniform and some of this has been explored in the nursing literature (Pearson et al 2001, Campbell et al 2000). The results suggest that the DN uniform had an important symbolic role to play in maintaining the professional boundary of the nurse and in reinforcing the professionalism of district nursing. It is an interesting area that needs further research.

A sense of professionalism also appears to be reinforced through being part of the DN team. All except one DN reported that their main support was from their DNs colleagues. In general the DN team was an essential component of successful support when dealing with bereaved people. It could be argued that the team helps to maintain both professional integrity and serves as a problems solving arena. Clinical supervision lacks the immediacy that DNs reported was required when dealing with clinical problems and so had a minimal role in providing support to the DNs. The importance of peer support in the DN team is an area that needs further study particularly if the introduction of an expanded role, with increased autonomy impacts on the dynamics of the team.

7.4.6 Strengths and limitations of the study

The following section will evaluate the quality of the research and suggest that it demonstrates methodological adequacy. Possible limitations to the study will be outlined. The four methodological criteria of trustworthiness and the five criteria of authenticity will then be applied to this research (Guba and Lincoln, 1989).

Dependability

Dependability relates to the concept of consistency and accuracy of the data and results. In essence the reader must be able to evaluate the adequacy of the researcher's analysis, from the elaborate descriptions outlined in the write up.

Through out the research process I maintained regular supervision with both supervisors to ensure my decisions were logical and appropriately based on the data. The inherent structure of framework analysis (Ritchie and Spencer, 1994) provided a useful method for analysing the data in a logical manner, enabling an open and explicit decision trail to be reported. I ensured that the accuracy of the data was verified at each stage starting with each transcript, which was checked against the original audio taped interview. Each subsequent stage of the research process was thoroughly documented in the method section and evidence of each stage of the analysis provided for scrutiny.

Credibility

Credibility is concerned with the accuracy of the match between the researcher's interpretation of the data and the constructed realities that exist in the minds of the participants. In other words does the researcher's interpretation of the data ring true for the participants? Credible research should provide depth of meaning and richness of understanding.

At each stage of the research process I attempted to ensure credibility. As a nurse I was conversant with the medical terminology, and jargon used. During each interview I endeavoured to clarify meaning with the nurse so that I had an accurate estimation of what they meant in response to each question. Each quote chosen from the text was selected as an exemplar to epitomise the meaning in that context. Although member checks were not carried out, each participant was offered the opportunity to read and comment on their transcripts. However none wished to do so.

Transferability

Within qualitative research transferability may occur across contexts when there are similar characteristics in those contexts. To enable transferability, the description of the findings and decision audit was explicit and detailed to maximise understanding. In addition the participants were sampled to maximise a range of views about bereavement support in the community.

Confirmability

The evidence for confirmability is derived from the audit trail. As outlined above I was explicit in each of my decisions, which were derived from the data and open to scrutiny. This makes the findings open to external judgements. I attempted at each stage to exclude my pre-conceptions and prior assumptions and based each decision on the evidence before me.

In summary it is argued that the research demonstrates sufficient methodological adequacy as evidenced from the four criteria of trustworthiness described above. Throughout the research process I have also attempted to comply with the criteria of authenticity, namely fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Guba and Lincoln, 1989; Erlandson et al, 1993). These will be briefly described.

Fairness

Based on the principles of fairness it was essential that I took into account the social context of the DN and their role as community nurses so that I could represent their views fairly. Continued informed consent was an important aspect of this and I was aware of shifts in the focus of power between myself and the DN throughout the interview. The issue of consent was addressed at the start of the interview as each participant signed a consent form. In addition when questions of a potentially emotional topic such as personal loss were asked, it was emphasised that the DN was not obliged to answer them. Each participant was given an equal voice in the analysis.

Ontological authenticity

Ontological authenticity was evidenced from comments made by several nurses during the interview about how talking about bereavement issues in the interview made them reconsider their perceptions about their bereavement work.

"... but I think definitely you no you asking the questions gives me you know you do realise that there are areas umm that you could sort of you could be improving our training and think of looking at sort of improving people."
DN 21 page 12

In addition written comments on the post interview questionnaire also provided evidence of changes to their practice

"We questioned our present ways of bereavement support. Several members of staff have since attended a bereavement support programme."
Comments from DN 8 in post interview questionnaire

Educative authenticity

Evidence for educative authenticity was found during the interview and in the feed back from the DNs in their post interview questionnaire. DN 4 is an exemplar of this:
"It made me think that we should have a more systematic approach to our work in this area to ensure a more effective follow up of people who have been bereaved. It also made me want to do further studies on the subject."
Comments from DN 4 in post interview questionnaire

Catalytic authenticity

Catalytic authenticity represents the way in which the research process has facilitated decision making by the participants who now have a greater potential for action.
One DN commented in her post interview questionnaire that she had decided to introduce sending condolence cards to bereaved people.

"Discussion with GP for surgery to send bereavement card. Staff nurse attending ENB 'Care of dying'" Comments from DN 21 in post interview questionnaire.

Tactical authenticity

Tactical authenticity suggests empowering the participants to act. The examples listed above show how the research process had an impact on some DNs practice and their desire to learn about bereavement issues. Several reported they had instigated changes in their practice and / or commenced courses about bereavement as a means of professional development.

Limitations to the study

The study focused upon the DNs within East and West Dorset, and may not have captured a wide range of views, opinions and practice. None of the DNs interviewed were from a minority ethnic group or worked in and ethnically diverse area. Future research should take the opportunity to interview DNs who work in more ethnically mixed populations, to explore a wider range of views and practice. I disclosed to each participant that I also had a nursing background. This may have facilitated some interviews but may have had an inhibitory effect on other participants. It is possible that there may have been a slight sense of suspicion in talking too freely about bereavement issues, which some DNs may have believed, could possibly be discussed with their managers, even though confidentiality and anonymity was assured.

Although a demographic information sheet was used to record background information about each DN at the time of the interview on reflection I feel I could have made more detailed field notes. Qualitative research was new to me and my lack of experience was reflected in the limited data collected following the interview. In future studies I would endeavour to construct a more detailed and comprehensive analysis of the interview reflecting my observations, thoughts and reflections on the interview process and participant.

7.5 Conclusions and recommendations

This final section will bring together the main findings from the three studies with particular emphasis on the DN studies (Chapters 5 and 6). I will then outline recommendations for the role of the DN service in the provision of bereavement support in the community.

7.5.1 Palliative care and bereavement support

The GP and DN play a pivotal role in the provision of palliative care in the community, and recent papers have highlighted the important link between palliative support and the provision of support to bereaved people, particularly those with mental health problems (Sainsbury Centre for Mental Health, 2002; NICE, 2003). The two DN studies in this thesis identified a lack of consensus between DNs about their role in the provision of bereavement support. This is a crucial factor because at present there are few protocols or guidelines for the primary care services in bereavement support while at the same time there is a drive towards a national framework that would incorporate the DN services both in the identification of bereaved people with mental health problems and the provision of support to those people (Sainsbury Centre for Mental Health, 2002; NICE, 2003). DN's need to develop a consensus of best practice in bereavement support that would be practical, manageable and flexible enough to incorporate local needs (e.g. mixed ethnicity).

The link between palliative support and bereavement support is important and should be considered at pre and post registration education. However, increasing demands are being made of the DN service and one must question whether repeated bereavement visits are an appropriate use of the DNs limited resources. Based on the findings outlined in Chapters 5 and 6 I propose that the DN service would be most effective in the initial assessment of bereaved people to identify those vulnerable or at risk and to then refer those in need to appropriate agencies. A long-term commitment to bereavement support does not appear to be the most effective use of the DN services unless they are able to provide a significant and specialise input to particular clients. Such specialised input would require both further training and a commitment from the DNs to maintaining the service.

7.5.2 Communication

All three studies identified deficits in communication and the evidence supports the fact that health professionals are often poor communicators (Audit Commission, 1993). The lack of follow-up by the two Community Psychiatric Nurses (CPN's) discussed in the first study, demonstrate the negative emotional impact on the surviving spouses. In addition it could be argued that this lacks courtesy and professionalism on behalf of the CPN's.

The findings from both the survey and interviews suggests a lack of knowledge of resources and poor communication between the members of the primary health care team about patients' deaths which is an issue that needs addressing. For example 21% of DNs surveyed reported that they did not know if their practice kept a death register and 40% were not sure if the practice had links with a bereavement service. Bereavement support requires good communication skills. The evidence suggests that investments in communication skills training for nurses and doctors have made little impact (Audit Commission, 1993). Many patients and carers questioned suggest health care professionals should receive better training (National Cancer Alliance, 1996). There is inadequate training in how to communicate with terminally ill patients or bereaved people, which may reflect a lack of priority in health care or alternatively the difficulty of teaching such a sensitive subject (Field and Kitson, 1986; Faulkner, 1992; Jeffrey, 1994, Lloyd-Williams and Lloyd-Williams, 1996). However, it is questionable whether such investments would make a significant different to practice for the majority of health care professionals or be an effective use of DN resources required for training.

However, being aware of possible resources at a local and national level is a different matter. Any development in bereavement support will only be successful if all staff are aware of available resources which they can discuss with bereaved people and other health care professionals in primary care. The creation of a death register would be an important step in improving the recording and communication of patient deaths in the practice.

Breaking bad news and dealing with bereaved people can be a particularly stressful event and it is important that all members of the PHCT receive some basic training in dealing with this. However, long-term bereavement support requires specialist knowledge and is best dealt with by appropriately trained people.

7.5.3 Assessment of bereaved people

The findings suggest that DNs do not use objective assessments when visiting bereaved people. Assessments were based on their intuition, empathy and prior knowledge of the bereaved person. The role of the DN involves the assessment of health needs of people in the community but in general most DNs lack appropriate skills and training in mental health assessments. The proposed role of the DN service in the assessment of bereaved people for mental health problems requires a possible expansion of the skill base to incorporate this. It is therefore important that the DN training incorporates the assessment and identification of at risk people and those with mental health problems.

The DN studies suggest that DNs could incorporate an assessment package as part of their bereavement visit. They would be ideally placed to perform such an assessment of risks factors, including the physical and mental health and in addition social risks factors which could include the identification of bereaved people who are lonely and vulnerable making them at an increased risk of mental and physical health problems. The development of such risk assessment tools in the community would be an interesting area for future research as they would help to shape the role of DNs in bereavement support.

Evidence from bereavement support groups in hospice settings suggests that targeting specific groups of bereaved people is the most effective use of resources. Parkes (1981) suggested that bereavement support services were best targeted at those who were at high risk and unsupported or perceived their families as unsupportive. There is evidence that providing support to specific vulnerable at risk people may help to reduce their consumption of drugs, alcohol, and tobacco and reduce the number of symptoms attributable to anxiety and tension. There is some evidence that bereaved carers of cancer patients who die at home may experience higher levels of psychological distress than carers of patients who die elsewhere (Addington-Hall & Karlsem, 2000). DNs could potentially play a key role in identifying at risk people and referring them to appropriate sources of support.

7.5.4 Providing bereavement support.

There findings of the DN studies suggest that the majority of DNs do not wish to develop specialist bereavement skills or that there would be available scope or resources to enable such an expanded role for the DN. The DNs interviewed identified themselves as supporters of bereaved people and not bereavement counsellors per se.

Current decision-making about bereavement support by DNs is mainly based on three key factors: prior knowledge of the bereaved family gained through palliative care of the deceased, intuition and empathy. The lack of guidelines has resulted in a wide variety of service provision, with little evidence to support any particular style. Bereavement support visits are mainly provided on an ad hoc basis and for most nurses lack structure. The lack of any structure to the visit promotes a social visit analogous to a 'cup of tea and chat' approach to bereavement support.

There has been no assessment of the importance of this type of contact with bereaved people, and this would be a useful area for further research. The social bereavement visit from the DN may provide a useful support mechanism for bereaved people. However, not all aspects of bereavement support have been welcomed and the professionalisation and medicalisation of bereavement is a contentious issue. Walter (1999) has suggested that as society becomes increasingly secularised, bereaved people who once turned to their families, community, and religious advisors for support are increasingly turning to health a professional, which has important implications for the primary care services. One DN interviewed observed how over her 30 year career she had witnessed changes in the local community due to the rapid changes in neighbours which had resulted in a loss of the sense of community. The old community comprised of friends, relatives and local acquaintances that would provide mutual support at times of loss, while in a rapidly changing modern neighbourhood there is a community of strangers who provide little support.

7.5.5 Provision of bereavement support: GP or DN?

There is some evidence from the UK that GP consultations may increase following bereavement (Parkes, 1964a, Tudiver et al 1995; Charlton et al, 2001). Any increase in GP consultation following bereavement has cost and resource implications for the primary care services. However at present there is no research to indicate the impact of DN bereavement visits on bereaved peoples' utilization of primary care services. Furthermore, any discussion of increased primary care interventions is likely to be resisted by the medical profession, which is understaffed and hard pressed to cope with current health care demands. In February 2002 The British Medical Association (BMA) published a discussion document in which they proposed a model of healthcare designed to overcome the shortages of GPs (BMA, 2002). In this document they suggest that the community nurse would also have an expanded clinical role, involving them undertaking a wider range of interventions. The practical implications of the BMA proposal would involve a radical change to the boundaries of the nursing role. Bereavement support may be one area in which nurses require an expansion of their skill-base, to reduce the increased use of health care services after bereavement and to identify people with bereavement related mental health problems.

7.5.6 The Voice of the bereaved

An area that remains under researched is the views of the service users (the bereaved person) and only a handful of studies have sought the views of the bereaved person in the community (Cartwright, 1982; Pearce, 1996; Lyttle, 2001). At present there is a danger of developing a 'paternalistic edge' to any proposed bereavement support from the DN team, because the service users have little input into any proposed service development. Therefore it is clear that one area that needs further research is the needs of bereaved people in the community. This is an area that needs evaluating if DNs are to be expected to expand their role in bereavement support. The views of the service user could be captured using qualitative methods, which would help gain an understanding of the importance of bereavement support from their perspectives.

It is unclear whether DN visits are helpful to bereaved people or what kind of information and support they would like from their Primary Care Team. In addition it is unclear what impact the DN visit have on the bereaved person. Do they provide emotional support? Do they help to reduce their utilization of other primary care services? (e.g. consultation with their GP). Further research would help inform both the future role of the DN and the most effective way that bereavement visits could be organised.

7.5.7 Policy implications, education and future research

Over all community services are also under a great deal of pressure and any expansion or extension of the CN role adds to the pressure. A report from the Audit Commission in 1999 outlined a number of problems faced by the district nursing services in the UK. Two thirds of Primary Care Trusts reported a fall in the number of qualified DNs, one in ten DNs were above the age of retirement and the numbers entering training have shrunk by one third since 1990. Overall this has reduced the capacity of the service. Added to this has been the increased demand on the services from an increasing older population of which 50% of those over 85 years see a DN, and an increase in early hospital discharge with specialist care (e.g. palliative care) which is increasingly being carried out within the home (Audit Commission, 1999). With increasing demands on service provision it is important that DNs feel supported in their work. Evidence from the DN studies suggests the crucial importance of the DN team in mutual support. This is an important area that must not be overlooked, and any modifications to the service should take into account the importance of the DN team. Changes to the role of the DN should consider the impact on the team dynamics in addition to that of the DN.

Any proposed expansion of the DN role has major implications for education and training. The results of the DN survey suggest a need for further training and education in the general area of bereavement. Only 25% of nurses reported pre-registration education as a source of information about bereavement. The main sources were practical experience on the job, reading nursing literature, and post-registration training. Evidence from those nurses interviewed suggests education about bereavement and grief predominantly promotes phase or stage theories. There have been theoretical advances in the way bereavement is perceived. Recent theories have outlined the importance of maintaining a relationship with the deceased and reintegrating them into the everyday life, rather than a discontinuation and moving on with life (Walter, 1996; Klaas et al, 1996). Such views may be at odds with the current theories taught at pre and post registration level. Future education needs to broaden its scope and take into account different theoretical perspective that may move away from the medical perceptions of grief as a disease with set stages to achieve before the bereaved have 'recovered'.

The research supports role clarification for the DN in general and the development of a limited role for the DN in the context of bereavement support following palliative care. Clarification about the extent of the DN role needs debating nationally and across professional bodies and any further expansion of the DN role, must be viewed within the context of developments within the primary health care team. DNs may have a useful role in the identification, assessment and referral of bereaved people at high risk. However, an important factor must be appropriate training in the assessment of bereaved people and the identification of those at risk or with special needs. The development of national bereavement guidelines would be useful as a basis for local bereavement visiting protocols. These should be evidence based and used to development DN services.

At present there is generally insufficient provision of information to bereaved people about the experience of bereavement, and available services and entitlements. There must be improved knowledge of available resources both within the practice and more effective interagency and inter-professional communication and cooperation. I would also recommend that all practices keep a death register and actively promote an environment of communication within the teams and across agencies. Available local resources need to be collated and developed at a local level to reflect the local needs of the population. Further research into the needs of bereaved people would be most fruitful so that user involvement is acknowledged and respected. In conjunction with this there should be easy access and better provision of information to bereaved people from all members of the PHCT. The research identified a number of issues about professional and personal role boundaries for DNs that needs further clarification. Finally the impact of socio-demographic changes on utilization of primary care resources is an area of particular interest, which could be expanded beyond the scope of this research topic.

7.5.8 A summary of recommendations

Future research:

- An evaluation of the needs of bereaved people in the community.
- Measurement of the impact of the provision of information about bereavement on the well-being of bereaved people.
- A measurement of the extent of mental health problems in a community sample of bereaved people.
- Clarification of the role of the DN in bereavement support.
- An evaluation of the impact of the DN visits on the bereaved people.

Recommendations for practice:

- Better training and awareness of bereavement issues at pre and post registration.
- For all DNs to have an increased awareness of available bereavement support at both a local and national level.
- To improve the provision of information to bereaved people
- For DNs to develop a coordinating role in bereavement support in the community. This would involve generic skills in the assessment of risks factors (psychological, social and health) in bereaved people and to have a network of specialist resources to refer people with particular risks or needs.
- For each general practice to have a death register.
- Where appropriate for specific individual DNs, who have particular interest in bereavement to develop specialised skills in bereavement support (e.g. counselling), rather than all DNs undergoing generic training.

Chapter 8: Conclusions and theoretical discussions

8.1 Introduction

In this chapter I will critically explore and reflect on the difficulties experienced while attempting to perform research with bereaved people. I will provide evidence to suggest that my research has been affected by a fundamental shift in society's view of bereaved people which may explain many of the difficulties experienced. This may also account for the ambivalence to bereavement support exhibited by health care professionals.

I will propose that many of my difficulties with gaining access to bereaved people and in carrying out the research process are best understood through consideration of three key factors:

- firstly the research was carried out against the socio-political backdrop of recent well publicised events which attracted the interest of the media and raised public awareness and anger towards the medical profession (The Kennedy Report, 2002; Alder Hey Report HMSO, 2001; The Shipman Inquiry, 2002)

- secondly I will argue that this research finding reflect evidence of a paradigm shift in the public perception of bereavement and their beliefs in the function of the primary care system which in part has resulted from a process of changes in the fabric of society that have been in development since the First World War

- finally, within many academic circles there has been a post-modernist shift in perception of the relationship between the deceased and those bereaved which has not always been recognised in the primary care system . There has been a general acceptance of the phase or stage theories as the 'correct' way to view bereavement and plan services, while recent theories have suggested a continued bond with the deceased (Walters, 1999 and Klass et al 1996). This has widened the knowledge gulf between 'academic bereavement research' and those working with bereaved people in primary care.

Taken together these changes have altered the perceptions of how bereaved people are perceived within society, the primary care system and the research community.

Recent events have also resulted in an increasingly defensive position in the research and medical community as to what is acceptable research. There has been an increasingly protective attitude towards 'vulnerable' people, of whom the bereaved are a constituent group. Much of this shift of focus appears directly related to an increasingly litigious society, changes in European and national law governing research, and recent government policy documents.

The remaining chapter will critically explore these various issues and relate them to the difficulties experienced in the research process. Finally I will consider the implications of my arguments and make suggestions about what this means for bereavement research, primary care and bereavement support.

8.2 An overview of the difficulties experienced while attempting to conduct research with bereaved people

8.2.1 The social, political and cultural context of my research

This critical exploration needs to be positioned within the wider context of ongoing changes in society together with several well publicised 'sensational events' which challenged public confidence in the scientific community and in particular the medical profession. The public enquiries resulted in considerable changes to certain aspects of the social and political landscape of British society with the development of a number of health care policies, which challenged the accepted authority, practices and power of the medical profession. Where previously the medical profession represented an 'all knowing' and powerful institution, the drive towards consumerism in the late twentieth Century coupled with the New Labour Government policies, requiring health services to consult with and involve service users, has seen a demand for the redistribution of power to the consumers of the health service. Society as a whole is no longer content to be the recipients of medical advice and practice, rather they are demanding increased information, and influence in the decision making process and services provided. The development of the internet has opened a gateway of information and increased communication between patients across the world. Self help groups have established websites and many doctors now experience the 'knowledgeable' patient accessing their care armed with the latest research, information and advice obtained through the Internet. To many the practices of Medicine have become an open arena where such practices can be criticised and decisions questioned.

Such consumer power has been encouraged through the political agenda. The Calman-Hine Report (Department of Health, 1995) set out seven key principles for the provision of cancer care. The fourth principle suggested that:

> *"The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important."* (Page 6)

This was later emphasized in the NHS Cancer Plan (Department of Health, 2000) within its section about empowering patients to improve services:

> *"At a local level cancer networks will be expected to take account of the views of patients and carers when planning services."* P 66.

In their book 'Improving Cancer Services Through Patient Involvement' Tritter et al (2004), provide a toolkit style approach to establishing user involvement in the direction and provision of cancer services.

These developments have provided a forum for the re-distribution of power from the medical profession to the public, and patients and carers now have a greater say in service provision. However, another impact of this change has been an increase in litigation against the health service, when service has not reached the acceptable standards, or errors have been made. The increasingly litigious society appears to be the direct result of the influence of North American practices in British society. The down side to this has been the emergence of defensive medical practice, with the potential for health professionals to avoid risk-taking treatments or to administer treatments that do not have worthwhile medical benefits simply to avoid liability.

Such a defensive stance appeared to be present at stages during my research process. There appeared to be a general sense of caution, if not reluctance to deal with any potentially 'controversial' research related to bereavement, which enveloped all levels of the research process starting with the key gate keepers to patient access, namely the Local Research Ethics Committees (LRECs). Later difficulties were experienced when dealing with general practitioners (GPs) and funeral directors. A possible explanation was that at the time of my research bereavement was a sensitive issue that had been highlighted in the media following the publication of two important and influential reports namely:

- The Alder-Hey inquiry into the retention of human tissue at the Royal Liverpool Children's Hospital which significantly raised the profile of the need to support bereaved families (HMSO, 2001).
- The Kennedy Report (2002) which centered on the Bristol Royal Infirmary. This inquiry resulted from a public outcry by parents of children who had died following paediatric cardiac surgery at the Bristol Royal Infirmary when it was revealed that tissue had, between 1984 and 1995, been systematically taken without permission at or after post-mortems. This resulted in a public Inquiry established in June 1998 by the Secretary of State for Health.

Each report produced a number of recommendations which influenced both public thinking and health professionals involved with patients and research. From the perspective of bereavement research and practice, the Alder-Hey enquiry recommended the need for the provision of information and support to bereaved parents, which the report suggested should be carried out by a bereavement advisor (HMSO, 2001). Any such adviser would be based within the hospital Trust. In an earlier interim report on guidelines for post mortem examinations the Chief Medical Officer had recommended that all NHS hospital trusts should designate a named individual in the trust who should be available to provide support and information to families of the deceased where a post-mortem was required (Department of Health, 2001a). The focus of attention was within the hospital and not the wider community.

The interim Kennedy Report entitled 'Removal and retention of human material', published in 2000, produced 69 recommendations including several focusing on bereavement related issues. It was acknowledged that although a senior member of the clinical team (e.g. the consultant surgeon) spoke to the parents about post-mortems it was common practice throughout the NHS for consent to a hospital post-mortem to be obtained by junior medical staff. In addition there was no evidence that any of the medical team had received any training in bereavement counselling or in breaking bad news, whether as part of their formal education or at the behest of the consultants. Recommendations included improved training for medical staff with appropriate consideration for privacy and sensitivity:

- Consultants should receive training in 'breaking bad news' and in seeking consent for a hospital post-mortem. (Recommendation 33)

- In the case of a death in hospital which gives rise to a Coroner's post-mortem, information about the Coroner's post-mortem should be given to the parents by a designated person within the hospital who has received all necessary and appropriate training. (Recommendation 10)

- Meetings concerning the Coroner's post-mortem, including its timing, should be conducted with proper regard for the circumstances of the parents. There should be a designated area with appropriate privacy. The parents should be offered support. If the parents agree, their GP should be contacted with a view to further care and counselling. (Recommendation 11)

In addition the provision of information regarding post mortems was recommended:

- As hospitals develop websites, a domain should be created concerned with 'bereavement' in which all the relevant information concerning post-mortems can be set out in an appropriate manner. (Recommendation 13)

Several of the findings raised public awareness that common medical practice was not always viewed as acceptable by the members of the public. On a more general level the media fuelled the issue of organ retention with sensationalism and branded it a 'scandal'. This in turn led to an increased public outcry and voiced mistrust in the procedure for post mortems and raised many questions about the public trust in the medical profession as a whole. The resulting lack of public confidence reflected a lack of recognition from the institution that families had concerns about their loved ones deceased bodies. It demonstrated a gulf between the public and the medical profession's views of what was acceptable practice.

To add to this melting pot of public suspicion and distrust of the medical profession there was the horrific case of the GP Dr Shipman, charged with the murder of one of his patients Kathleen Grundy. As the investigation continued it became apparent that Shipman had murdered over 200 of his patients over a period of more than 20 years, and was the most prolific known serial killer in British history. There followed a public outcry of disbelief over how a GP could simply murder so many patients and remain undetected for 20 years. The case sent chills down the spine of many people who demanded better policing of the profession and greater safeguards for the general public.

The subsequent Shipman Inquiry (2002) examined the local NHS primary care organisations and the General Medical Council (GMC) and their role in monitoring doctors. Again recommendations were made to ensure the protection of patients in the future.

These high profile cases resulted in an overhaul of both clinical governance and research governance procedures in the NHS (Research Governance Framework, Department of Health 2001b) and raised important questions about the culture within the NHS, Research community and the medical governing bodies such as the GMC.

8.2.2 Problems encountered with the initial applications made to the Local Research Ethics Committee (LREC)

It was against this backdrop of events that the first application was made to carry out my research to evaluate the impact of bereavement on the mental health of primary care patients. The repercussion of these major events caused a general sense of caution with respect to research, and a reluctance to deal with any potentially controversial research that related to tissue samples or 'vulnerable groups'. This caution appeared to envelop all levels of the research process particularly the Local Research Ethics Committees (LRECs).

In 1999 applications were made to two LRECs; first to the Southampton and South West LREC in August; and second to the Mid and North Hants LREC in November. The former application is described in Chapter 4 (Section 4.15) and it was their initial decision to withhold permission based on my perceived lack of experience in interviewing bereaved people and concerns that bereaved people might be unduly distressed during the interview and suffer subsequent emotional harm. However, the Southampton and South West LREC subsequently agreed that a small scale pilot study would be allowed, to ascertain the impact of the interviews on bereaved people, and to assess any risk involved. Their reluctance and hesitation to agree to the study appears to reflect the widespread general concerns at the time to ensure 'vulnerable groups' were not exposed to potential harm. I would argue that it was an overcautious decision that the researcher (myself) who was both a qualified nurse and a research nurse experienced in dealing with 'vulnerable groups' (patients with mental health problems, head injuries and learning disabilities) was not viewed as sufficiently experienced to deal with bereaved people. The consensus of the LREC appeared to be that bereaved people were a particularly vulnerable group who could only be accessed by those with 'specific training and experience in bereavement'. They appeared to be people afforded a special status.

On 17th November 1999 I attended the Mid and North Hants LREC meeting to outline the research proposal, namely to interview and assess bereaved people as part of a PhD thesis. Despite a general consensus that such research was laudable the committee declined permission for the research to take place within their area. Several key concerns were voiced which amounted to a fear that if bereaved people were interviewed it could put them at risk of suffering emotional harm and subsequent mental health problems including depression and self harm. It was proposed by the committee that asking a vulnerable group (the bereaved people) questions about their emotional well-being would put them at risk of harm. The LREC did not approve the proposed research and I decided not to pursue further attempts at applying to this committee. In both cases the LRECs raised similar concerns about the potential risk to bereaved people.

The views expressed by the LREC were actually contrary to the evidence found in the psychiatric literature regarding self-harm and depression. This appeared more a reflection of their discomfort with the area of research rather than a justified ethical or scientific concern. Contrary to the commonly expressed beliefs there is strong evidence to suggest that when those at risk talk about self-harm to health care professionals there is a significant reduction in the risk of self-harm. The LREC voiced the concerns that bereaved people were a special and 'vulnerable' group who required protection.

In contrast to their voiced fears, asking questions about depression does not cause depression; rather it aims to measure the person's current mental health status. If such acts of talking and asking questions induced a risk, most talking (psychological) therapies would be potentially harmful rather than helpful. The importance of talking is an area that is explored later in the chapter.

One could argue that the impact of what had happened in the context of organ retention may have been an influencing factor in the LRECs' decision making and therefore they were very cautious if not fearful of any potential repercussions from bereaved people.
In general the last few decades have seen our Society becoming increasingly risk aversive which may reflect both a rise in defensive practice due to increased litigation and also the public's failure to accept that much medical practice carries with it potential risk.

Payne and Field (2004) describe similar difficulties that they experienced during their research into bereavement support services. In one study they were forced to include a paragraph about the potential harm of participating in their research (involving an in-depth interview), that was originally developed to address patients' involvement in clinical trials. The authors correctly argue that this was not appropriate for a qualitative study and actually caused some concern amongst their participants.

This encounter proved enlightening and gave me the first glimpse into the future difficulties I would experience. It also highlighted a paradox, that for the LREC committees, bereaved people were perceived as a special and vulnerable group, who required protecting from enquiring researchers, yet because they are vulnerable were capable of functioning independently. This begs the question about the need for research into improving their care.

One should raise the question of why bereaved people are perceived by some professional groups to be vulnerable while others view them as 'normal' people who have experienced a loss. This issue appears to be at the crux of the issue about the medicalisation of grief.
The medicalisation of grief is a contentious issue. Walter suggests that there has been an increasing medicalisation of death over the last few centuries when Medicine began to augment religion at the deathbed. The medicalisation of grief, although following on from changes at the deathbed, has been a more recent phenomenon over the last century and something that has increased as society has become increasingly secularised and

turned to medicine rather than religion for explanations and support. This is an area that will be discussed later in the chapter.

It is clear that many research ethics committees are over protective of bereaved people and the bereavement service providers which limits access to potential research participants and limits research and the further development of service provision. However, it is also interesting to note that for both LRECs at no point were the views of the bereaved people expressed or sought before the decisions were made. Assumptions were made about the views of bereaved people which again appear to reinforce the view that they were perceived as a 'vulnerable' group incapable of making their own decisions. Being over protective is disempowering to bereaved people and reduces their choices.

8.3 Professional ambivalence towards bereavement

The research process unearthed ambivalence towards bereavement from the health professionals encountered. There were comments voiced by the LRECs, researchers, health care professionals, and funeral directors that expressed their belief that bereavement was a natural part of life and that the emotional expression of sadness, despair, and depression was a normal part of the grieving process. There was often an acknowledged appreciation of the research I was planning as 'worthwhile' and 'needed'. These various professionals often pointed out that bereavement was an under researched area. However, when approached with a request to carry out the research the actual responses of these different groups were at odds with their stated views. While telephoning some of the GPs and funeral directors there was often an uncomfortable sense (akin to embarrassment on the part of the professional) that this was an issue that was best left undisturbed. In essence I identified an implied yet unspoken ambivalence in that bereaved people were in reality perceived as a special and vulnerable (at risk) group who required protection during their period of grief. In reality they were not seen as an appropriate group to interview or ask to complete questionnaires because they were not perceived as 'normal' during their period of grief.

Ambivalence was also identified within the primary health care team. It was acknowledged that some bereaved people did experience emotional problems and would probably benefit from support. Some had appreciated the contact made by the primary care services. The findings however, suggested that there was little provision of such support and a lack of clarity in how best to deal with bereavement. Harris and Kendrick, (1998) reported that GPs as a group were divided over how best to deal with bereaved people between those who thought that active monitoring was warranted and those who thought that bereaved people should be left alone. Of the 13 patients recruited into the first study only two were recruited via GPs, although there were 15 GPs participating in the study, who had agreed in principle to recruit patients.

The findings from the district nurse survey and interviews revealed that as a group nurses also reported a spectrum of opinion about whether or not they should be actively following up bereaved people. The findings confirmed that many health care professionals have access to bereaved people and most could find the time and resources to offer support if required. However, few chose to intervene and others felt uncomfortable when they did so, which suggested uncertainty regarding the appropriate way to deal with bereaved people.

There was a general reluctance to 'invade the privacy' of the bereaved person during their time of grief among all professionals. Many also expressed a genuine fear of doing harm, because of 'a lack of appropriate and specialised training in dealing with bereaved people'. Again this demonstrated the way that the professionals positioned bereaved people so that they were perceived as 'separate', 'vulnerable' and different to other members of society. It is possible that for some nurses the reluctance to 'invade the privacy' of the bereaved person was due to their uncertainty about how to deal with them. To back up that concept I observed that a number of strategies seemed to be employed to ensure that most bereaved people were avoided in some way.

In total 75% of funeral directors contacted declined to participate in the study. The limited feedback from those who declined participation suggested that they were protective of the privacy of their clients (the bereaved) and were reluctant to expose them to outsiders (the researcher). This was expressed by several funeral directors some of whom acknowledged that the research was a good idea, but was better done elsewhere and not involving their clients. 'We are a small family business and have known the family of our clients for many years, we respect their privacy' was a response from some. This protective nature of the relationship again suggests that the group was perceived as vulnerable, yet denying access to researchers meant that vulnerability could not be explored in order to expose difficulties which may help them in the long-term.

Avoidance and restriction of access to bereaved people was also evidenced by the limits placed on health service provision to bereaved people particularly from the line managers of district nurses. This involved specific rules about what constituted acceptable and appropriate activity. When recording daily time and motion activities (using hand held computers to provide statistical data on nursing tasks for management purposes) bereavement support was not always perceived as legitimate nursing care and could not be coded, rather it was termed social care and was therefore perceived to be outside the remit of primary care. This apparently resulted in some district nurses deciding not to offer support.

If bereaved people are indeed recognised as an 'at risk' group of people why isn't appropriate support provided to them from primary care services? This raises a fundamental question of whether bereavement should be viewed as a problem at all in society, and whether it is a medical problem or a normal albeit difficult phase of life. One has to acknowledge that most bereaved people manage to cope with the experience of loss by drawing upon their own resources without the need for 'medical' intervention.

There is an obvious conflict between two views: bereavement and grief being a normal process, versus bereavement and grief as a special type of vulnerability. Such confusion in the minds of the health care professionals may be the cause of their uncertainty in how best to deal with bereaved people, in turn leading to a lack of accepted guidelines for practice in this area. The conflict appears often to be dealt with through avoidance of bereaved people. This uncertainty about whether bereavement is a health problem can also be seen in the limited input that both nurses and doctors receive during their training.

Many theories have focused on the intrapsychic processes of grief and developed models that define the 'normal' and accepted trajectory of the 'grieving process' in the form of phases or stages (Lindemann, 1944; Bowlby, 1980; Parkes 1971; Worden, 1981). However, others have argued that we should also consider the importance of the social and cultural aspects of bereavement (Klass et al, 1996; Walter, 1999). These theorists bring a sociological and anthropological perspective to bereavement with an emphasis on the impact of the social and cultural dimensions on the grieving processes. Observations of the research process indicate that those dealing with adult bereaved people (doctors, nurses, funeral directors) perceive a transition of personhood from the pre bereavement state where the person is an autonomous member of society to the post bereavement state where the bereaved person is temporarily regarded as an at risk, vulnerable non-autonomous member of society in need of protection. During this bereavement period bereaved people are considered as not fully functioning as members of society. It appears that a 'sick role' is attributed and expected of them irrespective of the views or behavior of the bereaved person. On reflection there appears to be a process of social construction by these professional groups of the 'normal' and acceptable activities of grief and bereavement which acts to attribute vulnerability to bereaved people. It is a process that reinforces the need to protect bereaved people and demonstrates that grief is perceived as anything but a 'normal process'. This was demonstrated through the restrictions placed on my research access to bereaved people.

It was apparent that those groups who acted as gate keepers, defined bereaved people as a special group, whom they felt obliged to protect from outside intrusion, and defined the terms and conditions of any access to them. Such rules were made on behalf of bereaved people without their knowledge and consent and reflect a protective, arguably paternalistic attitude. I suggest that this social construction of grief enables some professionals to cope with the ambivalence felt towards bereaved people by acting to legitimise their avoidance of the bereaved person, thereby ensuring that they do not feel discomfort when in the presence of those bereaved. By assuming bereaved people are vulnerable and in need of protection, decisions about access can be made at an 'emotional distance', without being questioned.

8.4 Attempting to understand the ambivalence around bereavement support from an historical perspective.

My research identified a palpable tension in society with most of the professional groups expressing reluctance to approach and disturb bereaved people during their time of grief. Loss and grief is a major life event and the cultural expressions of loss have been the subject of many academic debates drawing on the perspectives of archeology, history, sociology, psychology and more recently psychiatry.

Walters argues that over the last century many of the customs surrounding mourning in Britain appear to have been lost and today modern death appears to lack an agreed set of rituals or format about how to behave. It is possible to identify transitions in mourning practices following the large number of male deaths experienced during the First World War. This had a major impact on prescribed rituals surrounding death and the private and public expression of grief. At the start of the war it was accepted that middle and upper class women conformed to an elaborate social etiquette of mourning dress. However, so great were the numbers of dead soldiers that the country would have been plunged into black (Payne et al, 1999).

Walters, (1999) suggests that by the end of the twentieth century society is in a state of transition from the modern era to the postmodern era, fuelled in part by an increasingly secularized and consumer driven society. A variety of factors have influenced these changes including the rise in consumerism, advances in medical technology, the breakdown of the extended family, and increased social and geographical mobility resulting in a breakdown in the sense of community. He goes on to suggest that the shift of focus has been moving from the community expression of grief (traditional modernist death) towards an individualized expression of dying and death which he terms neo modernist and post modernist. However, bereavement today may or may not conform to previously prescribed rituals and so the rules of appropriate behaviour, dress code and funeral may all be as individual as the deceased. The loss of a standard and acceptable code of conduct makes dealing with death a confusing time.

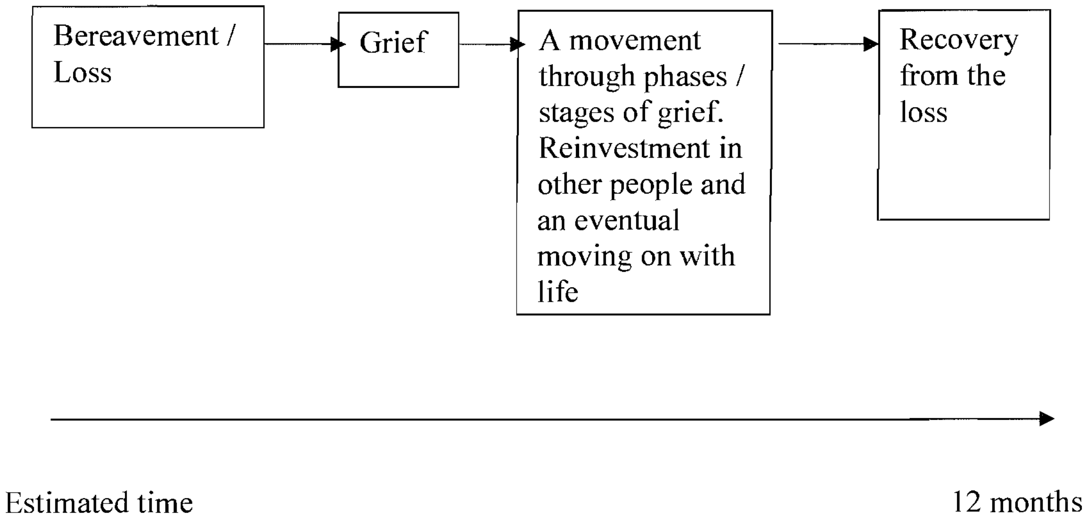
Over the last century British society has witnessed the power and influence of the Christian church and established religion in general decline as society becomes increasingly secularised. It has also been observed that there has been a corresponding shift from a spiritual 'explanation' and provision of support (once provided by the church) to a medical 'explanation' even though there remains a relative absence of support at the time of grief. This medicalisation of grief can be traced to the writings of Freud, (1917) and the psychoanalytic schools, Lindemann (1944), Engel, (1961), and then later in the more prescriptive phase or stage theories of grief suggested by authors such as Bowlby, (1980), Parkes, (1971) and Kubler-Ross, (1969).

The development of theories to explain grief and provide a trajectory of expected outcome has been a bone of contention with several recent theories. Implicit in this world view is the underlying notion of the bereaved person 'moving on' with their life and 'reinvesting' energy into a new relationship. This fits nicely with the medical model and the concept of cure. However, recent theorists have questioned the received view that bereaved people 'move on' with their life and have provided evidence that it has always been known that bereaved people do not 'forget' their loss, rather they integrate their memories of the deceased into their life to form a continued bond (Klass et al, 1996). Another important but overlooked aspect of grief has been the process of talking about the deceased, which appears to play a major role in reorganising and re-evaluating the memory of the deceased person. The biographical model of grief proposed by Walter argues that the purpose of dialogue about the deceased person is to provide a means whereby the various facets of the deceased are brought together and eventually located in the life of those bereaved. The possible importance of talking is discussed next.

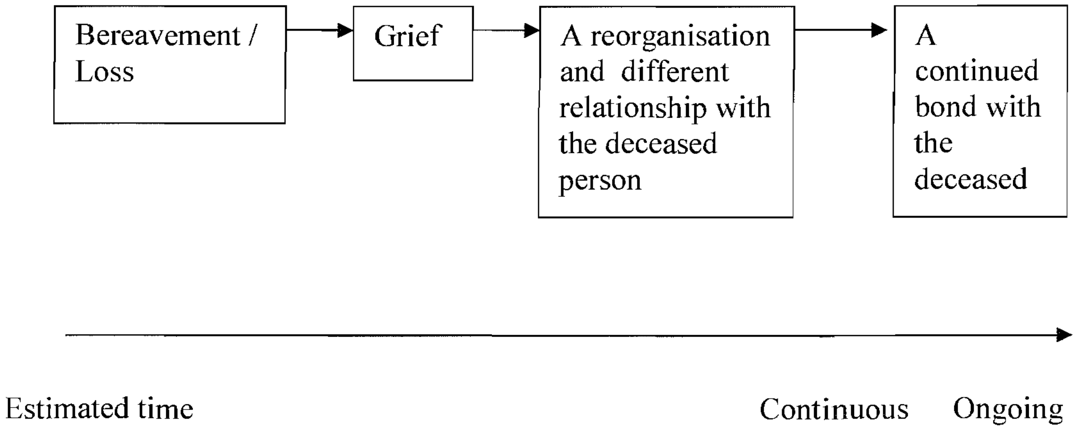
These contrasting views between the phase / stage models and those with a continued attachment can be seen in Diagram 8.1 below.

Diagram 8.1

Medical model of grief as an illness



Continued bond with the deceased (Klass et al, 1996)



8.4.1 The importance of talking.

Another important shift in society has been a change in the importance of talking about loss which has developed in the latter part of the twentieth century. During and post World War II, self reliance and stoicism was highly valued. People tended not to display emotions or talk about their losses. However, the latter part of the last century has seen the emergence of an increased and open acceptance of talking as a means of coping with loss and an encouragement to talk about problems in general. The psychological or talking therapies have become accepted means of dealing with psychological problems. Many nurses who performed bereavement visits acknowledged this and planned the visit so that they would have plenty of time to enable the bereaved person to talk. However, it could also be argued that the promotion of 'talking' may reflect the views of certain influential groups in society particularly the educated 'middle classes', while other groups (those of the older generation) maintain the traditional British stoicism. The twentieth century saw a great rise in psychological treatments starting with the psychoanalytic school of Freud and today we still have a significant provision of psychological therapies.

In general openness to talking was something which I experienced during the interviews with bereaved people. Most found some comfort in talking through the events surrounding the death, even if they were painful. However, some bereaved people maintained a 'brave face' when talking about the death and kept their emotions suppressed, while others cried when the memories were upsetting. This was contrary to the expectations voiced by the LRECs who suggested that speaking with bereaved people could cause them harm or put them at an increased risk. Instead I found a willingness to talk about the deceased at great length. In addition the concerns raised by LRECs, health professionals and funeral directors, about research involving bereaved people, is not supported by the international literature which demonstrates that most bereaved people appreciate the opportunity to discuss their experiences during the research interviews (Payne and Field, 2004). In a study by Dyregrov (2004) of the experience of bereaved parents' participation in bereavement research, it was reported that all of the 64 people interviewed found the research experience to be 'positive or very positive' and none regretted participation.

In addition a survey by Ingleton (2004) of carer satisfaction with end of life care service provision in Wales reported that although only one fifth of respondents had talked to someone from health and social services, four out of five had found that helpful. Similarly positive feedback was received from 12 of the 13 bereaved people I interviewed. Those who participated may have found participation in the research rewarding. However, there was no information about non-respondents, who may not have shared the opinions of those who participated. Taken as a whole these findings appear to refute the notion that bereaved people should be protected from researchers. They appear capable of making decisions for themselves about participation.

The concept of Klass et al (1996) of a continued bond with the deceased also enables an understanding of the importance of talking about the deceased through which bereaved people construct a 'living' bond with the deceased within their everyday life. Walters Biographical model of grief supports the importance of talking with others about the deceased person. He argues the process enables bereaved people to construct a biography of the deceased which they incorporate into their daily life (Walter, 1996). Although Walter has developed an erudite model of grief it is open to several criticisms. Most of his ideas have been developed from his own personal experiences of loss, which may not reflect the experiences of other bereaved people in the wider population. In addition, Walter's writes from an articulate sociological 'academic' perspective that privileges talking as the essential component in constructing a biography of the deceased. It is an area that needs further investigation before more general claims can be made.

Relf (1997) similarly identified the importance of talking in the grief process. In her research Relf focused on the support offered to bereaved people by volunteers working at a hospice. One aspect of her study involved a client opinion survey in which she explored the views of 48 bereaved clients in response to the support provided. Four themes emerged from the clients' descriptions of what was thought to be helpful:

being listened to; feeling understood; talking to someone who was not part of their social network and gaining information about grief.

The impact of simply having a person to talk to appears an important factor in helping some people cope with their loss and enables them to manage their grief. In the past talking was enabled through contact with faith leaders such as the vicar or priest, and withother family members. As society has become increasingly secularised together with other changes outlined earlier there has been a change or removal of available support networks which has for some reduced the availability of someone to talk with. In addition more people live alone particularly elderly women with approximately 50% living in a single persons household.

However, there is reluctance on the part of some bereaved people to turn to psychological counsellors because of both the cost and possible social stigma associated with seeking psychological help. Again it appears that some bereaved people have looked towards primary care services to fill the gap and provide that support. Societal changes appear to funnel people towards one of the few remaining free and socially acceptable sources of help; the primary care team. Unfortunately, the world view of the primary care system may not always fit with that of societal expectation and demand. This appears to be at the heart of the ambivalence demonstrated by the professionals encountered in my research.

8.5 Understanding the findings in light of the changing roles in society

I suggest that my research was carried out at an important juncture at the end of the twentieth century that captured a shift in the public perception of bereavement and also an ongoing transition in the way that British society perceives the role of the medical profession, particularly primary care. When taken together they help explain many of the difficulties experienced in the research process and also enable us to identify and focus on issues for future development.

The changes that have occurred in society over the last century have had an important impact on the available support network to which people turn to at times of crisis. The support provided tended to be spiritual or 'common sense' guidance. However, with an increase in the impact of medicine, society has turned to science and medicine for answers and cures to major life events which are understood as physical. Although most theories provide a psychological account of grief (e.g. Freud 1917;Bowlby, 1980; Parkes 1971; Worden, 1981).) increasingly since World War II psychiatry has attempted to draw associations between psychological states and an underlying neurochemical basis. The relatively new medical specialties of psychopharmacology and the neurosciences have been at the forefront in the development of pharmaceutical products and other treatments to treat mood disorders and behavioural problems. The change in society's expectations for a 'solution' or 'quick fix' has also been a factor in the push for bereaved people to look to doctors, nurses and counsellors for help rather than a religious leader.

There is an increasing expectation in society for Medicine, particularly the primary care services, to provide answers and solutions to everyday problems. The medical model with its emphasis on treatment and cure may not provide a satisfactory framework for dealing with grief. The evidence suggests that typically medical intervention only occurs when the grief extends beyond a 'normal' prescribed time limit (usually six to 12 months) or is excessive or disruptive to normal function. However, the medical model represents one particular world view of bereavement. Alternative world views which integrate spiritual, socio-cultural, and behavioural aspects of bereavement, subscribe to more individual perception of the grief experience, rather than suggesting a 'normal' grief process with a stage of 'recovery'. Grief may not be a thing to be 'cured' as the root cause is irreversible. Rather it may be considered a normal event to be weathered until the bereaved person can once again cope with life.

To add to the confusion it is apparent that health professionals are receiving expert policy advice about how to deal with bereaved people which also defines them as an at risk group, vulnerable group. This opinion has been voiced through several recent policy publications, including the NICE Guidance on Support and Palliative Care Services

(NICE, 2004), the mental health assessment of bereaved people (Sainsbury Centre for Mental Health, briefing 19; 2002), and from the Alder-Hey inquiry into the retention of human tissue at the Royal Liverpool Children's Hospital which raised the profile of the need to support bereaved families (HMSO, 2001).

The message from these sources is contrary to some current practice in primary care and one that suggests that health care professionals should actively engage with bereaved people, and provide information about grief and services for them to access. It is proposed that there is a role for health professionals in the assessment and identification of those who may be at risk, and the need to provide a bereavement service framework which provides appropriate management through the involvement of agencies in the public and voluntary sector. Some may interpret such guidelines as making the assumption that all bereaved people need information and support. On the contrary there is wide variation in how people react to loss and their need for support. Much is dependent upon personality, previous life experiences, coping styles and available personal and social resources. The latter includes such diverse sources as family, friends, faith groups and wider social structures. Such individual differences need to be acknowledged and respected in the provision of any future bereavement care services. Defining all bereaved people as 'vulnerable' and 'at risk' may foster a culture of dependency rather than be helpful.

Unfortunately the lack of basic agreement on the position of bereaved people in society is a major stumbling block both to research and the development of appropriate bereavement service provision, which is ultimately to the detriment of many bereaved people. On the one hand it is probable that a large proportion of the provision of information and support is likely to come from the primary health care team rather than faith groups and other community institutions. However, given their current ambivalence to bereavement support one should also question the role of the primary care services and ask whether primary care should be the main or key provider of bereavement support, as this raises the potential risk of medicalising what is a normal life transition for most people. Furthermore can the primary care services afford the time and resources to allocate to bereavement support?

Although the NICE Guidance is specific to palliative care services for adults with cancer (NICE, 2004), it represents an opening of the door for bereaved people to enter into the health arena. The NICE Guidance provides an integrated three tier model that utilised and promotes some aspects of social support and self reliance by explicitly stating that not all bereaved people require 'services' to cope with their loss. Level one provides guidance about the provision of information, which should empower bereaved people to make choices and to cope independently with their own support network. It is estimated that the majority of bereaved people (60%) should be dealt with at this level. Approximately 30% of bereaved people may require more formal 'support', although they may not require 'professional intervention'. The remaining 10% of bereaved people may require professional services e.g. counselling to help them to cope with their loss. It is likely that in future the NICE Guidance on good practice will be expanded to include bereaved people outside the palliative care services.

The current ambiguities in professional and societal attitudes to bereaved people makes the planning and delivery of services very complex. The emerging involvement of primary care services in bereavement support needs to clarify that role. At the moment most bereavement services are provided by the voluntary sector e.g. CRUSE and do not have a clear rationale for their service provision, which is an issue that needs to be explored.

If primary care is to have a role in bereavement support one should ask whether services should primarily focus on the prevention of psychopathology or on enhancing the bereaved person's independence and ability to develop coping strategies to deal with the life transition. The primary care services have an identified responsibility to provide information (NICE level one support) and offer support from none-professional and professional services (NICE level one and two) to people who need it (NICE, 2004). This would help to promote the view that in general most bereaved people cope with their loss without the need for medical intervention. There may however, be some people who need referral to professional service e.g. counsellors or psychiatrists to help them deal with their loss (NICE level three) and it is judging the amount of support required that is crucial in getting the balance right. This is something that is offered by the NICE model (NICE, 2004) and would provide a useful framework in which services could be developed to reduce the risk of medicalisation and to promote self reliance as the primary goal and best practice (Level 1 provision). GPs and DNs have access to bereaved people, and the skills to assess and monitor bereaved people and may be perceived as the appropriate focal point to coordinate the resources. However, the primary care services would also need to develop a wider network of organisations and services particularly local community support, which is one of the key suggestions for level 2 support (NICE, 2004) which may be better placed to offer more individualised support to bereaved people depending on their specific needs. This could include faith groups, self help and support groups or local bereavement support groups. More specific advice and support could be offered by financial advisors or the Citizens Advice Bureau.

8.6 Conclusions

This research was carried out during a time of important changes in the sociopolitical and health landscape. At each stage of the research process I identified a palpable tension in attitudes towards bereaved people.

Over the last decade there has been a change in the public perception of the medical profession brought about by the findings of several reports which have rocked public confidence. In addition there has been a shift in the public attitude towards death and bereavement over the last century, particularly since the First World War. British society has become increasingly secularised and consumer orientated which has changed the focus of how bereavement is perceived. This has resulted in a shift away from spiritual explanations, support and advice from the Christian Church towards a medical explanation with higher expectations of treatment and cure. The primary care system has now become the main point of contact for bereaved people. However, there remains an ambivalence from health care professionals about how to deal with bereaved people. Bereaved people are labelled as vulnerable and at risk by many health care professionals and access to them is restricted or avoided.

These findings have a number of implications for future bereavement research, primary care and bereavement support. If current views predominate bereavement research will be restricted in its focus. Limited access to bereaved people ensures that their voice will not be heard and their contribution to the research process will be limited. This will be to the detriment of future research. This thesis has identified a need for primary care to clarify its stance towards bereavement support. At present it has no clear view which severely restricts its influence and the development of appropriate bereavement support. The issue of the medicalisation of grief also requires careful consideration.

An additional conclusion is that recent theoretical developments in bereavement research have not been incorporated into modern thinking. Many health professionals still have limited awareness of theoretical developments, beyond the traditional phase / stage theories which contributes to the gulf between academic researchers in bereavement and those who will plan future services. Bereavement support services need to consider the importance of social change on the way bereavement is viewed within the general population.

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Appendix

Appendix 1	CIS-R
Appendix 2	SF36
Appendix 3	SSQ
Appendix 4	ITG
Appendix 5	GEI
Appendix 6	Demographic details of participants
Appendix 7	Helpfulness questionnaire
Appendix 8	GP questionnaire
Appendix 9	Post interview questionnaire
Appendix 10	Letter to GP
Appendix 11	Letter to bereaved people
Appendix 12	Letter to FD & FD letter to bereaved people
Appendix 13	DN letter and questionnaire
Appendix 14	Interview schedule with DNs
Appendix 15	Consent form for DNs
Appendix 16	Thematic framework (9 themes)
Appendix 17	Chart for theme 4
Appendix 18	Post interview letter and questionnaire

Appendix 1

CIS-R

☐ A **Somatic symptoms**

A1 Have you had any sort of ache or pain in the past month?

Yes	1	→ A3
No	2	→ A2

A2 During the past month have you been troubled by any sort of discomfort, for example, headache or indigestion?

Yes	1	→ A3
No	2	→ **Go to section B**

A3 Was this ache or pain/discomfort brought on or made worse because you were feeling low, anxious or stressed?

If informant has more than one pain/discomfort, refer to ANY of them

Yes	1	→ A4
No	2	→ **Go to section B**

A4 In the past seven days, including last (DAY OF WEEK), on how many days have you noticed the ache or pain/discomfort?

4 days or more	▨	→A5
1 to 3 days	2	→A5
None	3	→ A9

A5 In total, did the ache or pain/discomfort last for more than 3 hours on any day in the past week/on that day?

Yes	▨
No	2

A6 In the past week, has the ache or pain/discomfort been

Running prompt

very unpleasant	▨
a little unpleasant	2
or not unpleasant	3

A7 Has the ache or pain/discomfort bothered you when you were doing something interesting in the past week?

Yes	▨
No/has not done anything interesting	2

A8 How long have you been feeling this ache or pain/discomfort as you have just described?

less than 2 weeks	1
2 weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

A9 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at A4, A5, A6 and A7.

Ring '0' if sum of codes is zero ...	0
or	
enter score ⟶	

*

B Fatigue

B1 Have you noticed that you've been getting tired in the past month?

Yes	1	→ **B3**
No	2	→ **B2**

B2 During the past month, have you felt you've been lacking in energy?

Yes	1	→ **B3**
No	2	→ **Go to section C**

B3 Do you know why you have been feeling tired/lacking energy?

Yes	1	→ (a)
No	2	→ **B4**

(a) What is the main reason? Can you choose from this card?

Code one only

Problems with sleep	1	→ **B4**
Medication	2	
Physical illness	3	
Working too hard (inc. housework, looking after baby)	4	
Stress, worry or other psychological reason	5	
Physical exercise	6	→ **Go to Section C**
Other	7	→ **B4**

B4 In the past seven days, including last (DAY OF WEEK) on how many days have you felt tired/lacking in energy?

4 days or more	[redacted]	→ **B5**
1 to 3 days	2	
None	3	→ **B10**

B5 Have you felt tired/lacking in energy for more than 3 hours in total on any day in the past week?

	Yes	▨
	No	2

B6 Have you felt so tired/lacking in energy that you've had to push yourself to get things done during the past week?

	Yes, on at least one occasion	▨
	No	2

B7 Have you felt tired/lacking in energy when doing things that you enjoy during the past week?

	Yes, at least once	▨	→ **B9**
	No	2	→ **B8**
Spontaneous	Does not enjoy anything	3	

B8 Have you in the past week felt tired/lacking in energy when doing things that you used to enjoy?

	Yes	▨
	No	2

B9 How long have you been feeling tired/lacking in energy in the way you have just described?

less than 2 weeks	1
2 weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

B10 **Sum codes which you have ringed in the shaded boxes at B4, B5, B6, B7 and B8.**

Ring '0' if sum of codes is zero ...	0
or	
enter score →	

* C Concentration and forgetfulness

C1 In the past month, have you had any problems in concentrating on what you are doing?

Yes, problems concentrating	1	
No	2	

C2 Have you noticed any problems with forgetting things in the past month?

Yes	1	
No	2	

C3 **Interviewer code**

Informant has problems concentrating or forgets things (coded 1 at C1 or C2)	1	→ C4
Others	2	→ **Go to section D**

C4 Since last (DAY OF WEEK), on how many days have you noticed problems

4 days or more	▨	→ C5
1 to 3 days	2	
None	3	→ C9

C5 **Informants who had concentration problems**

DNA: others (coded 2 at C1)	1	→ C7

In the past week could you concentrate on a TV programme, read a newspaper article or talk to someone without your mind wandering?

Yes	2	
No/not always	▨	

C6 In the past week, have these problems with your concentration actually stopped you from getting on with things you used to do or would like to do?

Yes	▨	
No	2	

C7 **Informants who had memory problems**

DNA: others (coded 2 at C2) …………	1	→ C8

(Earlier you said you had been forgetting things.)
Have you forgotten anything important in the past seven days?

Yes …………………	▨
No …………………	2

C8 How long have you been having problems with your concentration/memory as you have described?

less than 2 weeks …………………	1
2 weeks but less than 6 months …………	2
6 months but less than 1 year …………	3
1 year but less than 2 years ……………	4
2 years or more …………………	5

C9 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at C4, C5, C6, and C7.

Ring '0' if sum of codes is zero …	0
or	
enter score ⟶	

* D Sleep problems

D1 In the past month, have you been having problems with trying to get to sleep or with getting back to sleep if you woke up or were woken up?

Yes	1	→ **D3**
No	2	→ **D2**

D2 Has sleeping more than you usually do been a Problem for you in the past month?

Yes	1	→ **D3**
No	2	→ **Go to section E**

D3 On how many of the past seven nights did you have problems with your sleep?

4 nights or more	▨	→ **D4**
1 to 3 nights	2	→ **D4**
None	3	→ **D11**

D4 Do you know why you are having problems with your sleep?

Yes	1	→ **(a)**
No	2	→ **D5**

(a) Can you look at this card and tell me the main reason for these problems?

Code one only

Noise	1
Shift work/too busy to sleep	2
Illness/discomfort	3
Worry/thinking	4
Needing to go to the toilet	5
Having to do something (e.g. look after baby)	6
Tired	7
Medication	8
Other	9

D5 **Informants who had problems trying to get (back) to sleep**

DNA: others (coded 2 at C2)	1	→ **D8**

Thinking about the night you had the least sleep in the past week, how long did you spend trying to get to sleep? (If you woke up or were woken up I want you to allow a quarter of an hour to get back to sleep).

Only include time spent trying to get to sleep

Less than ¼ hour	3	→ **Go to Dll and code '0'**
At least ¼ hour but less than 1 hr	1	→ **D7**
At least 1 hr but less than 3 hrs	2	→ **D7**
3 hrs or more	3	→ **D6**

D6 In the past week, on how many nights did you spend 3 or more hours trying to get to sleep?

4 nights or more	1
1 to 3 nights	2
None	3

D7 Do you wake up more than two hours earlier than you need to and then find you can't get back to sleep?

Yes	1	→ **D10**
No	2	→ **D10**

D8 Informants who slept more than usual

Thinking about the night you slept the longest in the past week, how much longer did you sleep compared with how long you normally sleep for?

Less than ¼ hour	3	→ **Go to Dll and code '0'**
At least ¼ hour but less than 1 hr	▨	→ **D10**
At least 1 hr but less than 3 hrs	▨	→ **D10**
3 hrs or more	▨	→ **D9**

D9 In the past week, on how many nights did you sleeps for more than 3 hours longer than you usually do?

4 nights or more	▨
1 to 3 nights	2
None	3

D10 How long have you been having problems with your sleep as you have described?

less than 2 weeks	1
2 weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

D11 Interviewer check:

Sum codes which you have ringed in the shaded boxes at D3, D5, D6, D8 and D9.

Ring '0' if sum of codes is zero ... **(or if coded 3 at D5 or D8)**	0
or	
enter score ——————→	

* E Irritability

E1 Many people become irritable or short tempered at times, though they may not show it.

Have you felt irritable or short tempered with those around you in the past month?

Yes/no more than usual	1	→ E3
No	2	→ E2

E2 During the past month did you get short tempered or angry over things which now seem trivial when you look back on them?

Yes	1	→ E3
No	2	→ Go to section F

E3 Since last (DAY OF WEEK), on how many days have you felt irritable or short tempered/angry?

4 days or more	▨	→ E4
1 to 3 days	2	→ E4
None	3	→ E11

E4 What sort of things made you irritable of short tempered/angry in the past week?

E5 In total, have you felt irritable or short tempered/angry for more than one hour (on any day in the past week)/?

Yes	■
No	2

E6 During the past week, have you felt so irritable or short tempered/angry that you have wanted to shout at someone, even if you haven't actually shouted?

Yes	■
No	2

E7 In the past seven days, have you had arguments, rows or quarrels or lost your temper with anyone?

Yes	1	→ (a)
No	2	→ E10

(a) Did this happen once or more than once (in the past week)?

Once	1	→ E8
More than once	2	→ E9

E8 Do you think this was justified?

Yes, justified	2	→ E10
No, not justified	▨	

E9 Do you think this was justified on every occasion?

Yes	2	→ E10
No, at least one was unjustified	▨	

E10 How long have you been feeling irritable or short tempered/angry as you have described?

less than 2 weeks	1
two weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

E11 Interviewer check:

Sum codes which you have ringed in the shaded boxes at E3, E5, E6, E8 and E9.

Ring '0' if sum of codes is zero ...	0
or	
enter score ⟶	

* F Worry about physical health

E1 Many people get concerned about their physical health. In the past month, have you been at all worried about your physical health?

Include women who are worried about their pregnancy

Yes .... 1 → F3

No/concerned .... 2 → F2

F2 **Informants who have no problems with physical health**

DNA: has a physical health problem shown at 11a page 6. .... 1 → **Go to Section G**

During the past month, did you find yourself worrying that you might have a serious illness?

Yes .... 1 → F3

No .... 2 → **Go to section G**

F3 Thinking about the past seven days, including last (DAY OF WEEK), on how many days have you found yourself worrying about your physical health/ that you might have a serious physical illness?

4 days or more .... ▨ → F4

1 to 3 days .... 2 → F4

None .... 3 → F8

F4 In your opinion, have you been worrying too much in view of your actual health?

Yes .... ▨

No 2

F5 In the past week, has this worrying been

Running prompt

very unpleasant .... ▨

a little unpleasant 2

or not unpleasant? 3

F6 In the past week, have you been able to take your mind off your health worries at least once, by doing something else?

Yes	2
No, could not be distracted once	▨

F7 How long have you been worrying about your physical health in the way you have described?

less than 2 weeks	1
two weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

F8 Interviewer check:

Sum codes which you have ringed in the shaded boxes at F3, F4, F5 and F6

Ring '0' if sum of codes is zero ...	0
or	
enter score ⟶	☐

* G Depression

G1 Almost everyone becomes sad, miserable or depressed at times.

Have you had a spell of feeling sad, miserable or depressed in the past month?

Yes	1	
No	2	

G2 During the past month, have you been able to enjoy or take an interest in things as much as you usually do?

Yes	1	
No/no enjoyment or interest	2	

G3 **Interviewer check:**

Code First that applies

Informant felt sad, miserable or depressed (coded 1 at G1)	1	→ G4
Informant unable to enjoy or take an interest in (coded 2 at G2)	2	→ G5
Others	3	→ **Go to section I, page 20**

G4 In the past week have you had a spell of feeling sad, miserable or depressed?

Use informant's own words if possible

Yes	1	→ **See G5**
No	2	

G5 **Informants who were unable to enjoy or take an interest in things**

DNA: coded 1 at G2	1	→ **See G6**

In the past week have you been able to enjoy or take an interest in things as much as usual

Use informant's own words if possible

Yes	2	
No/no enjoyment or interest	▨	

G6 **Informants who felt sad, miserable or depressed or unable to enjoy or take an interest in things in the <u>past week</u> (coded 1 at G4 or G5)**

DNA:	1	→ **Go to G11**

Since last (DAY OF WEEK) on how many days have you felt sad, miserable or depressed/unable to enjoy or take an interest in things?

4 days or more	[illegible]
1 to 3 days	2
None	3

G7 Have you felt sad, miserable or depressed/unable to enjoy or take an interest in things for more than 3 hours in total (on any day in the past week)?

Yes	1
No	2

G8 What sorts of things made you feel sad, miserable or depressed/unable to enjoy or take an interest in things in the past week? *Can you choose from this card?*

Ring cod(s) in column (a).

	(a) **Code all that apply**	(b) **Code one only**
Members of the family	01	01
Relationship with spouse/partner	02	02
Relationships with friends	03	03
Housing	04	04
Money/bills	05	05
Own physical health (inc. pregnancy).	06	06
Own mental health	07	07
Work or lack of work (inc. student) ...	08	08
Legal difficulties	09	09
Political issues/the news	10	10
Other	11	11
Don't know/no main thing	99	99

(b) **DNA: Only one item coded at (a)**	1	→ **G9**

What was the main thing?
Ring code in column (b)

G9 In the past week when you felt sad, miserable or depressed/unable to enjoy or take an interest in things, did you ever become happier when something nice happened, or when you were in company?

Yes, at least once	2
No	1

G10 How long have you been feeling sad, miserable or depressed/unable to enjoy or take an interest in things as you have described?

less than 2 weeks	1
two weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years..................	4
2 years or more	5

G11 Interviewer check:

Sum codes which you have ringed in the shaded boxes at G5, G6, G7 and G9.

Ring '0' if sum of codes is zero ...	0
or	
enter score ⟶	

*	H If Depressive Ideas

H1 **Informants who scored 1 or more at section G, Depression**

DNA: Others (coded 0 or blank at G11) ……..	1	→ **Go to section I**

I would now like to ask you about when you have been feeling sad, miserable or depressed/unable to enjoy or take an interest in things. In the past week, was this worse in the morning or in the evening, or did this make no difference?

Prompt as necessary	in the morning ………………..	1
	in the evening ………………..	2
	no difference/other ……………..	3

H2 Many people find that feeling sad, miserable or depressed/ unable to enjoy or take an interest in things can affect their interest in sex. over the past month, do you think your interest in sex has

Running prompt		increased ………………………	1
		decreased ………………………	2
	or	has it stayed the same? ………..	3
Spontaneous		Not applicable …………….	4

H3 When you have felt sad, miserable or depressed/ unable to enjoy or take an interest in things in the past seven days,

		Yes	No
Individual prompt	have you been so restless that you couldn't sit still? ……………..….	1	2
	have you been doing things more slowly, for example, walking more slowly? …….	1	2
	Have you been less talkative than normal?	1	2

H4 Now, thinking about the past seven days have you on at least one occasion felt guilty or blamed yourself when things went wrong when it hasn't been your fault?

Yes, at least once …….	1
No ………………..	2

H5 During the past week, have you been feeling you are not at good as other people?

	Yes	....	▨	
	No	....	2	

H6 Have you felt hopeless at all during the past seven days, for instance about your future?

	Yes	....	▨	
	No	....	2	

H7 **Interviewer check:**

Informant felt guilty, not as good others or hopeless (coded 1 at H4 or H6)	....	1	→ **H8**
Others (coded 2 at H4, H5 and H6)	....	2	→ **read H10**

H8 In the past week have you felt that life isn't worth living?

	Yes	....	▨	→ **H9**
Spontaneous:	Yes, but not in the past week	......	2	→ **read H10**
	No	....	3	

H9. In the past week, have you thought of killing yourself?

	Yes	....	▨	→ **(a)**
Spontaneous:	Yes, but not in the past week	.....	2	→ **read H10**
	No	....	3	

(a) Have you talked to your doctor about these thoughts (of killing yourself)?

	Yes	....	1	→ **read H10**
Spontaneous:	No, but has talked to other people	....	2	→ **read (b)**
	No	....	3	

(b) (You have said that you are thinking of committing suicide) Since this is a very serious matter it is important that you talk to your doctor about these thoughts. → **read H10**

H10 (Thank you for answering those questions on how you have been feeling. I would now like to ask you a few questions about worrying.)

H11 **Interviewer check:**

Sum codes that you have ringed in the shaded boxes at H4, H5, H6, H8 and H9.

Maximum score in this section is 5

Ring ‘0’ if sum of codes is zero .. 0

or

enter score ⟶ ☐

* I Worry

I 1 (The next few questions are about worrying)
In the past month, did you find yourself worrying more than you needed to about things?

Yes, worrying	1	→ I 3
No/concerned	2	→ I 2

I 2 Have you had any worries at all in the past month?

Yes	1	→ I 3
No	2	→ **Go to Section J**

I 3 (a) Can you look at this card and tell me what sorts of things you worried about in the past month?

Ring code(s) in column (a)

	(a) **Code all that apply**	(b) **Code one only**
Members of the family	01	01
Relationship with spouse/partner	02	02
Relationships with friends	03	03
Housing	04	04
Money/bills	05	05
Own physical health (inc. pregnancy)	06	06
Own mental health	07	07
Work or lack of work (inc. student)	08	08
Legal difficulties	09	09
Political issues/the news	10	10
Other	11	11
Don't know/no main thing	99	99

(b) **DNA: Only one item coded at (a)**	1	→ I 4

What was the main thing you worried about?

Ring code in column (b).

I 4 Interviewer check:

Informant worries about physical health (coded 06 at I 3(a))	....	1	See Instruction below, then go to I 5
Others (not coded 06 at I 3(a))	....	2	→ I 6

Make a note to go to section F to record this worry about physical health, if not already recorded.

I 5 Interviewer check:

Informant is only worried about physical health (only code 06 is rung at I 13(a))	....	1	→ Go to section J
Informant had other worries (I 3(a) is multi-coded)	....	2	→ read (a)

(a) For the next few questions, I want you to think about the worries you have had other than those about your physical health

---

I 6 On how many of the past seven days have you been worrying about things (other than your physical health)?

4 days or more	....	[redacted]	→ I 7
1 to 3 days	....	2	→ I 7
None	....	3	→ I 11

I 7 In your opinion, have you been worrying too much in view of your circumstances

Refer to worries other than those about physical health

Yes	....	[redacted]
No	....	2

I 8 In the past week, has this worrying been:

Running prompt

Refer to worries other than those about physical health

very unpleasant	....	[redacted]
a little unpleasant	....	2
or not unpleasant	....	3

I 9 Have you worried for more than 3 hours in total on any one of the past seven days?

Refer to worries other than those about physical health

Yes …………………	1
No …………………	2

I10 How long have you been worrying about things in the way that you have described?

Less than 2 weeks …………………	1
2 weeks but less than 6 months …………………	2
6 months but less than 1 year …………………	3
1 year but less than 2 years …………………	4
2 years or more …………………	5

I 11 Interviewer check:

Sum codes which you have ringed in the shaded boxes at I6, I7, I8 and I9.

Ring '0' if sum of codes is zero ..	0
or	
enter score ⟶	

* J Anxiety

J 1 Have you been feeling anxious or nervous in the past month?

Yes, anxious or nervous …………	1	→ J3
No …………………	2	→ J2

J 2 In the past month, did you ever find your muscles felt tense or that you couldn't relax?

Yes …………………	1
No …………………	2

J 3 Some people have phobias; they get nervous or uncomfortable about specific things or situations when there is no real danger. For instance they may get nervous when speaking or eating in front of strangers, when they are far from home or in crowded rooms, or they may have a fear of heights. Others become nervous at the sight of things like blood or spiders.

In the past month have you felt anxious, nervous or tense about any specific things or situations when there was no real danger?

Yes …………………	1
No …………………	2

J 4 **Interviewer check:**

Informant reports anxiety and also a phobia (coded 1 at J1 or J2, and coded 1 at J3) ……………	1	**→ J5**
Informant reports only general anxiety (coded 1 at J1 or J2, and coded 2 at J3) ……………	2	**→ J7**
Others (coded 2 at J1 and J2, and coded 1 or 2 at J3	3	**→ Go to section K**

J 5 In the past month, when you felt anxious/nervous/tense, was this always brought on by the phobia about some specific situation or thing or did you sometimes feel generally anxious/nervous/tense?

Always brought on by phobia ………………	1	**→ Go to section K**
Sometimes felt generally anxious ………………	2	**→ J6**

J 6 The next questions are concerned with general anxiety/nervousness/tension only.
I will ask you about the anxiety which is brought on by the phobia about specific things or situations later.

On how many of the past seven days have you felt generally anxious/nervous/tense?

4 or more days	1	→ J8
1 to 3 days	2	
None	3	→ J12

J 7 On how many of the past seven days have you felt generally anxious/nervous/tense?

4 or more days	[illegible]	→ J8
1 to 3 days	2	
None	3	→ J12

J 8 In the past week, has your anxiety/nervousness/tension been:

Running prompt

	very unpleasant	[illegible]
	a little unpleasant	2
or	not unpleasant	3

J 9 In the past week, when you've been anxious/nervous/tense, have you had any of the following symptoms?

Yes	[illegible]	→ (a)
No	2	→ J10

(a) Which of these symptoms did you have when you felt anxious/nervous/tense?

Code all that apply

Heart racing or pounding	1
Hands sweating or shaking	2
Feeling dizzy	3
Difficulty getting your breath	4
Butterflies in stomach	5
Dry mouth	6
Nausea or feeling as though you wanted to vomit	7

If the informant had any of these symptoms, check J9 is coded 1, 'Yes'

J 10 Have you felt anxious/nervous/tense for more than 3 hours in total on any one of the past seven days?

Yes	▨
No	2

J 11 How long have you had these feelings of general anxiety/nervousness/tension as you described?

Less than 2 weeks	1
2 weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

J 12 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at J6, J7, J8, J9 and J10

Ring '0' if sum of codes is zero ..	0
or	
enter score →	

* K Phobias

K 1 **Interviewer check:**

Informants who had phobic anxiety in the past month (coded 1 at J3)	1	→ K3(a)
Others	2	→ K2

K 2 Sometimes people avoid a specific situation or thing because they have a phobia about it. For instance, some people avoid eating in public or avoid going to busy places because it would make them feel nervous or anxious.

In the past month, have you avoided any situation or thing because it would have made you feel nervous or anxious, even though there was no real danger?

Yes	1	→ **K3(b)**
No	2	→ **See section L**

K 3 (a) Which of the following situations or things listed made you the most anxious/nervous/tense in the past month?
Ring code at (b), then go to K4

(b) Can you look at this card and tell me, which of these situations or things did you avoid the most in the past month?

Code one only

Crowds or public places, including travelling alone or being far from home	1
Enclosed spaces	2
Social situations, including eating or speaking in public, being watched or stared at	3
The sight of blood or injury	4
Any specific single cause including insects, spiders and heights	5
Other (specify)	6

K 4 Informants who had phobic anxiety in past month **DNA: others (coded 2 at K1)** …………………	1	→ K7

In the past seven days, how many times have you felt nervous or anxious about (SITUATION/THING?)

4 times or more …………………	1	→ K5
1 to 3 times …………………	2	→ K5
None …………………	3	→ K6

K In the past week, on those occasions when you felt anxious/nervous/tense did you have any of the following symptoms? → K7

Yes …………………	1	→ (a)
No …………………	2	→ K6

(a) Which of these symptoms did you have when you felt anxious/nervous/tense?

If informant had any of these symptoms, check K5 is coded 1, "Yes"

Heart racing or pounding …………………	1
Hands sweating or shaking …………………	2
Feeling dizzy …………………	3
Difficulty getting your breath …………	4
Butterflies in stomach …………………	5
Dry mouth …………………	6
Nausea or feeling as though you wanted to vomit …………………	7

K 6 In the past week, have you avoided any situation or thing because it would have made you feel anxious/nervous/tense even though there was no real danger?

Yes …………………	1	→ K7
No …………………	2	→ K8

K 7 How many times have you avoided such situations or things in the past seven days?

1 to 3 times …………………	[redacted]
4 times or more …………………	[redacted]
None …………………	3

K 8 **Informants who had phobic anxiety/avoidance in the Past week (coded 1 or 2 at K4 or K7)**

DNA: Others	1	→ K9

How long have you been having these feelings about these situations/things as you have just described?

Less than 2 weeks	1	
2 weeks but less than 6 months	2	
6 months but less than 1 year	3	
1 year but less than 2 years	4	
2 years or more	5	

K 9 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at K4, K5 and K 7

Ring '0' if sum of codes is zero	0
or	
enter score ———————→	

* L **Panic**

L 1 Informants who have felt anxious in the past month

DNA: Others (coded 3 at J4, page 23)		1	→ **Go to Section M**

Thinking about the past month, did your anxiety or tension ever get so bad that you got in a panic, for instance make you feel that you might collapse or lose control unless you did something about it?

Yes	....	1	→ L2
No	....	2	→ **Go to section M**

L 2 How often has this happened in the past week?

Once	....	▨	→ L3
More than once	....	▨	
Not at all	....	3	

L 3 In the past week, have these feelings of panic been:

Running prompt	a little uncomfortable or unpleasant	....	2
	or have they been very unpleasant or unbearable?	....	▨

L 4 Did this panic/the worst of these panics last for longer than 10 minutes?

Yes	....	▨
No	....	2

L 5 Are you relatively free from anxiety between these panics?

Yes	....	1
No	....	2

L 6 Informants who had phobic anxiety

DNA: Others (coded 2 at K 1)	....	1	→ L7

Refer to situation/thing at K 3.

Is this panic always brought on by (SITUATION/THING?)

Yes	....	1
No	....	2

L 7 How long have you been having these feelings of panic as you have described?

less than 2 weeks	....	1
2 weeks but less than 6 months	....	2
6 months but less than 1 year	....	3
1 year but less than 2 years	....	4
2 years or more	....	5

L 8 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at L2, L3 and L4.

Ring '0' if sum of codes is zero 0

or

enter score ⟶ ☐

M Compulsions

M 1 In the past month, did you find that you kept on doing things over and over again when you knew you had already done them, for instance checking things like taps or washing yourself when you had already done so?

Yes	....	1	→ M2
No	....	2	→ Go to section N

M 2 On how many days in the past week did you find yourself doing things over again that you had already done?

4 days or more	....		→ M3
1 to 3 days	....	2	
None	....	3	→ M9

M 3 Since last (DAY OF WEEK) what sorts of things have you done over and over again?

M 4 During the past week, have you tried to stop yourself repeating (BEHAVIOUR)/doing any of these things over again?

Yes	....	
No	....	2

M 5 Has repeating (BEHAVIOUR)/doing any of these things over again made you upset or annoyed with yourself in the past week?

Yes, upset or annoyed	....	
No, not at all	....	2

M 6 **If more than one thing is repeated at M3**

DNA: Others ……………………	1	→ M7

Thinking about the past week, which of the things you mentioned did your repeat the most times?

Describe here …………………………………………………………… → M7

M 7 Since last (DAY OF WEEK), how many times do you repeat (BEHAVIOUR) when you had already done it?

Refer to BEHAVIOUR at M6, if applicable

3 or more repeats ……………………	1
2 repeats ……………………	2
1 repeat ……………………	3

M 8 How long have you been repeating (BEHAVIOUR)/any of the things you mentioned in the way which you have` described?

Less than 2 weeks ……………………	1
2 weeks but less than 6 months ……………………	2
6 months but less than 1 year ……………………	3
1 year but less than 2 years ……………………	4
2 years or more ……………………	5

M 9 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at M2, M4, M5 and M7.

Ring '0' if sum of codes is zero ………	0
or	
enter score ——————→	

☐ *

N Obsessions

N 1 In the past month did you have any thoughts or ideas over again that you found unpleasant and would prefer not to think about, that still kept on coming into your mind?

Yes	1	→ N2
No	2	→ Go to section O

N 2 Can I check, is this the same thought or idea over and over again or are you worrying about something in general?

Same thought	1	→ N3
Worrying in general	2	→ See instruction below, then go to section O

Make a note to go to section I to record this worry, if not already recorded.

N 3 What are these unpleasant thoughts or ideas that keep coming into your mind?

Do not probe
Do not press for answer

N 4 Since last (DAY OF WEEK), on how many days have you had these unpleasant thoughts?

4 days or more	[redacted]	→ N5
1 to 3 days	2	→ N5
None	3	→ N9

N 5 During the past week, have you tried to stop yourself thinking any of these thoughts?

Yes	[redacted]
No	2

N 6 Have you become upset or annoyed with yourself when you had these thoughts in the past week?

Yes, upset or annoyed	[redacted]
Not at all	2

N 7 In the past week, was the longest episode of having such thoughts:

Running prompt

	a quarter of an hour or longer	▨
or	was it less than this?	2

N 8 How long have you been having these thoughts in the way which you have just described?

Less than 2 weeks	1
2 weeks but less than 6 months	2
6 months but less than 1 year	3
1 year but less than 2 years	4
2 years or more	5

N 9 **Interviewer check:**

Sum codes which you have ringed in the shaded boxes at N4, N5, N6 and M7.

Ring '0' if sum of codes is zero	0
or	
enter score ⟶	☐

*

O Overall effects

Informants who scored 2 or more on any section, A to N

DNA: Others (All section scores 0 or 1 on check card)

1 → **Add total scores for each section**

Now I would like to ask you how all of these things that you have told me about have affected you overall.

In the past week, has the way you have been feeling ever actually stopped you from getting on with things you used to do or would like to do?

Yes	…………………	1	→ (a)
No	…………………	2	→ (b)

(a) In the past week, has the way you have been feeling stopped you doing things once or more than once?

Once	…………………	1	→ **Add total scores for each section**
More than once	…………………	2	

(b) Has the way you have been feeling made things more difficult even though you have got everything done?

Yes	…………………	1	→ **Add total scores for each section**
No	…………………	2	

Appendix 2

SF-36

SF-36 HEALTH SURVEY

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

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3. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

(circle one number on each line)

<u>ACTIVITIES</u>	**Yes, Limited A Lot**	**Yes, Limited A Little**	**No, Not Limited At All**
a. **Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports**	1	2	3
b. **Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf**	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking half a mile	1	2	3
i. Walking one hundred yards	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

(circle one number on each line)

—	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Were limited in the kind of work or other activities	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

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5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the amount of time you spent on work or other activities	1	2
b. Accomplished less than you would like	1	2
c. Didn't do work or other activities as carefully as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

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8. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

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10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time............................1

Most of the time............................2

Some of the time............................3

A little of the time............................4

None of the time............................5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

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Appendix 3

SSQ

The social support questionnaire (6-item abbreviated version):

For each question firstly lists all the people you know (excluding yourself) who you can count on for help or support in the manner described. Give the person's initials and their relationship to you e.g. brother, friend etc. (max. 9 people)

Then circle how satisfied you are with the overall support you have.

If you have no support for a question then tick no-one but still rate the level of satisfaction you feel.

A Who can you really count on to be dependable when you need help?

1 .... (relationship to you).....................
2. .... (relationship to you).....................
3. .... (relationship to you).....................
4. .... (relationship to you).....................
5. .... (relationship to you).....................
6. .... (relationship to you).....................
7. .... (relationship to you).....................
8. .... (relationship to you).....................
9. .... (relationship to you).....................

Very Satisfied Very dissatisfied

6 5 4 3 2 1

B Who can you really count on to help you feel more relaxed when you are under pressure or tense?

1 .... (relationship to you).....................
2. .... (relationship to you).....................
3. .... (relationship to you).....................
4. .... (relationship to you).....................
5. .... (relationship to you).....................
6. .... (relationship to you).....................
7. .... (relationship to you).....................
8. .... (relationship to you).....................
9. .... (relationship to you).....................

Very Satisfied Very dissatisfied

6 5 4 3 2 1

C Who accepts you totally, including both your best and worst points?

1 .... (relationship to you).......................
2. .... (relationship to you).......................
3. .... (relationship to you).......................
4. .... (relationship to you).......................
5. .... (relationship to you).......................
6. .... (relationship to you).......................
7. .... (relationship to you).......................
8. .... (relationship to you).......................
9. .... (relationship to you).......................

Very Satisfied Very dissatisfied

6 5 4 3 2 1

D Who can you really count on to care about you, regardless of what is happening to you?

1 .... (relationship to you).......................
2. .... (relationship to you).......................
3. .... (relationship to you).......................
4. .... (relationship to you).......................
5. .... (relationship to you).......................
6. .... (relationship to you).......................
7. .... (relationship to you).......................
8. .... (relationship to you).......................
9. .... (relationship to you).......................

Very Satisfied Very dissatisfied

6 5 4 3 2 1

E Who can you really count on to help you feel better when you are feeling generally down in the dumps?

1 .... (relationship to you)......................

2. .... (relationship to you)......................

3. .... (relationship to you)......................

4. .... (relationship to you)......................

5. .... (relationship to you)......................

6. .... (relationship to you)......................

7. .... (relationship to you)......................

8. .... (relationship to you)......................

9. .... (relationship to you)......................

Very Satisfied					Very dissatisfied
6	5	4	3	2	1

F Who can you count on to console you when you are very upset?

1 .... (relationship to you)......................

2. .... (relationship to you)......................

3. .... (relationship to you)......................

4. .... (relationship to you)......................

5. .... (relationship to you)......................

6. .... (relationship to you)......................

7. .... (relationship to you)......................

8. .... (relationship to you)......................

9. .... (relationship to you)......................

Very Satisfied					Very dissatisfied
6	5	4	3	2	1

Appendix 4

ITG

Inventory of Traumatic Grief (ITG)

Holly Prigerson, Ph.D., Stanislav Kasl, Ph.D., Selby Jacobs, M.D., M.P.H.

Please mark the circle next to the answer that best describes how you have been feeling over the past <u>month</u>. The blanks refer to the deceased person over whom you are grieving.

Almost never = less than once a month
Rarely = once a month or more, less than once a week
Sometimes = once a week or more, less than once a day
Often = once every day
Always = several times every day

1. The death of ___________ feels overwhelming or devastating.

   1 - almost never
   2 - rarely
   3 - sometimes
   4 - often
   5 - always

2. I think about ___________ so much that it can be hard for me to do the things I normally do.

   1 - almost never
   2 - rarely
   3 - sometimes
   4 - often
   5 - always

3. Memories of ___________ upset me.

   1 - almost never
   2 - rarely
   3 - sometimes
   4 - often
   5 - always

4. I feel that I have trouble accepting the death.

   1 - almost never
   2 - rarely
   3 - sometimes
   4 - often
   5 - always

5. I feel myself longing and yearning for ___________.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

6. I feel drawn to places and things associated with ___________ .

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

7. I can't help feeling angry about ___________ 's death.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

8. I feel disbelief over ___________ 's death.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

9. I feel stunned, dazed, or shocked over ___________ 's death.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

10. Ever since ___________ died it is hard for me to trust people.

1 - no difficulty trusting others
2 - a slight sense of difficulty
3 - some sense
4 - a marked sense
5 - an overwhelming sense

11. Ever since ___________ died I feel like I have lost the ability to care about other people or I feel distant from people I care about.

1 - no difficulty feeling close or connected to others
2 - a slight sense of detachment
3 - some sense
4 - a marked sense
5 - an overwhelming sense

12. I have pain in the same area of my body, some of the same symptoms, or have assumed some of the behaviors or characteristics of __________.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

13. I go out of my way to avoid reminders of ___________.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

14. I feel that life is empty or meaningless without ___________.

1 - no sense of emptiness or meaninglessness
2 - a slight sense of emptiness or meaninglessness
3 - some sense
4 - a marked sense
5 - an overwhelming sense

15. I hear the voice of ___________ speak to me.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

16. I see ___________ stand before me.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

17. I feel like I have become numb since the death of ___________.

1 - no sense of numbness
2 - a slight sense of numbness
3 - some sense
4 - a marked sense
5 - an overwhelming sense

18. I feel that it is unfair that I should live when ___________ died.

1 - no sense of guilt over surviving the deceased
2 - a slight sense of guilt
3 - some sense
4 - a marked sense
5 - an overwhelming sense

19. I am bitter over ___________ 's death.

1 - no sense of bitterness
2 - a slight sense of bitterness
3 - some sense
4 - a marked sense
5 - an overwhelming sense

20. I feel envious of others who have not lost someone close.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

21. I feel like the future holds no meaning or purpose without ___________.

1 - no sense that the future holds no purpose
2 - a slight sense that the future holds no purpose
3 - some sense
4 - a marked sense
5 - an overwhelming sense

22. I feel lonely ever since ___________ died.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

23. I feel unable to imagine life being fulfilling without ___________.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

24. I feel that a part of myself died along with the deceased.

1 - almost never
2 - rarely
3 - sometimes
4 - often
5 - always

25. I feel that the death has changed my view of the world.

1 - no sense of a changed world view
2 - a slight sense of a changed world view
3 - some sense
4 - a marked sense
5 - an overwhelming sense

26. I have lost my sense of security or safety since the death of ___________.

1 - no change in feelings of security
2 - a slight sense of insecurity
3 - some sense
4 - a marked sense
5 - an overwhelming sense

27. I have lost my sense of control since the death of ___________.

1 - no change in feelings of being in control
2 - a slight sense of being out of control
3 - some sense of being out of control
4 - a marked sense
5 - an overwhelming sense

28. I believe that my grief has resulted in significant impairment in my social, occupational or other areas of functioning.

1 - no functional impairment
2 - mild functional impairment
3 - moderate
4 - severe
5 - extreme

29. I have felt on edge, jumpy, or easily startled since the death?

1 - no change in feelings of being on edge
2 - a slight sense of feeling on edge
3 - some sense
4 - a marked sense
5 - an overwhelming sense

30. Since the death, my sleep has been

1 - basically okay
2 - slightly disturbed
3 - moderately disturbed
4 - very disturbed
5 - extremely disturbed

31. How many months after your loss did these feelings begin? _______ months.

32. How many months have you been experiencing these feelings? ________ months (0 = never)

33. Have there been times when you did not have pangs of grief and then these feelings began to bother you again?

1 - yes
2 - no

34. Can you describe how your feelings of grief have changed over time?

____
____
____
____
____

For Office Purposes Only

35. If interviewer-administered, does rater consider this respondent to have syndromal level Traumatic Grief?

1 - yes
2 - no

36. Does respondent meet the following criteria for Traumatic Grief?

Criterion A1:

- The death of a significant other is a prerequisite for completion of the ITG.

Criterion A2:

Separation Distress: at least 3 of the 5 following symptoms must be greater than or equal to 4 ("often," "very," or "marked").

- Q2, Q3, Q5, Q6, Q22

Criterion B:

Traumatic Distress: at least 6 of the 12 following symptoms must be greater than or equal to 4.

- Q4, Q7, Q8, Q9, Q11, Q13, Q14, Q17, Q19, Q21, Q23, Q26

Criterion C:

- Q32 is greater than 2 months.

Criterion D:

- Q28 is greater than or equal to 4 ("severe").

1 - yes
2 - no

Appendix 5

GEI

GRIEF EXPERIENCE INVENTORY

[illegible]

1. Immediately after the death I felt exhausted.
2. I tend to be more irritable with others.
3. I am strongly preoccupied with the image of the deceased.
4. I frequently experience angry feelings.
5. It is not difficult to maintain social relationships with friends.
6. My arms and legs feel very heavy.
7. I am unusually aware of things related to death.
8. It seems to me that more could have been done for the deceased.
9. I showed little emotion at the funeral.
10. I felt a strong necessity for maintaining the morale of others after the death.

11. I feel cut-off and isolated.
12. I rarely take aspirins.
13. I feel reluctant to attend social gatherings.
14. I was unable to cry at the announcement of the death.
15. I have feelings of guilt because I was spared and the deceased was taken.
16. I have a special need to be near others.
17. I often experience confusion.
18. I feel lost and helpless.
19. I am comforted by believing that the deceased is in heaven.
20. I have had frequent headaches since the death.

21. It was difficult to part with the clothing and personal articles of the deceased.
22. It was necessary to take sleeping pills after the death.
23. The yearning for the deceased is so intense that I sometimes feel physical pain in my chest.
24. I cry easily.
25. I have taken tranquilizers since the death.
26. I experience a dryness of the mouth and throat.
27. I feel restless.
28. Upon first learning of the death I had a dazed feeling.
29. Concentrating upon things is difficult.
30. I have feelings of apathy.

31. I experienced a feeling when the death occurred that "something died within me."
32. Aches and pains seldom bother me.
33. I find I am often irritated with others.
34. I could not cry until after the funeral.
35. I feel that I may in some way have contributed to the death.
36. I find myself performing certain acts which are similar to ones performed by the deceased.
37. I made the funeral arrangements.
38. I lack the energy to enjoy physical exercise.
39. I rarely feel enthusiastic about anything.
40. I feel that grief has aged me.

41. I have never dreamed of the deceased as still being alive.
42. I find myself frequently asking "why did the death have to happen in this way?"
43. I sometimes have difficulty believing the death has actually occurred.
44. I feel a strong desire to complete certain unfinished tasks the deceased had begun.
45. I have often dreamed of times when the deceased was living.
46. I am often irritable.
47. I have dreamed of the deceased as being dead.
48. I feel extremely anxious and unsettled.
49. I feel tenseness in my neck and shoulders.
50. Sometimes I have a strong desire to scream.

51. I am so busy that I hardly have time to mourn.
52. I feel anger toward God.
53. I have the urge to curl up in a small ball when I have attacks of crying.
54. I feel the need to be alone a great deal.
55. I rarely think of my own death.
56. I find it difficult to cry.
57. Looking at photographs of the deceased is too painful.
58. Life has lost its meaning for me.
59. I have no difficulty with digestion.
60. I have had brief moments when I actually felt anger at having been left.

61. I have no trouble sleeping since the death.
62. I have a hearty appetite.
63. I feel healthy.
64. It comforts me to talk with others who have had a similar loss.
65. I yearn for the deceased.
66. I seldom feel depressed.
67. I have the feeling that I am watching myself go through the motions of living.
68. Life seems empty and barren.
69. There are times when I have the feeling that the deceased is present.
70. I often take sedatives.

71. I have frequent mood changes.
72. The actions of some people make me resentful.
73. My feelings are not easily hurt.
74. I am losing weight.
75. Small problems seem overwhelming.
76. I sometimes feel guilty at being able to enjoy myself.
77. I frequently have diarrhea.
78. I often wish I could have been the one to die instead.
79. I have lost my appetite.
80. I sometimes talk with the picture of the deceased.

81. I am not interested in sexual activities.
82. At times I wish I were dead.
83. It is hard to maintain my religious faith in light of all the pain and suffering caused by the death.
84. I seem to have lost my energy.
85. I dread viewing a body at the funeral home.
86. I find myself idealizing the deceased.
87. I have problems with constipation.
88. I frequently take long walks by myself.
89. I avoid meeting old friends.
90. I have a special need for someone to talk to.

91. It often feels as if I have a lump in my throat.
92. I sometimes find myself unconsciously looking for the deceased in a crowd.
93. I seem to have lost my self-confidence.
94. I drink more alcohol now than before the death.
95. After the announcement of the death I thought, "This could not be happening to me."
96. I have nightmares.
97. The thought of death seldom enters my mind.
98. I have never worried about having a painful disease.
99. Funerals sometimes upset me.
100. I would not feel uneasy visiting someone who is dying.

101. I often worry over the way time flies by so rapidly.
102. I have no fear of failure.
103. I am close with only a few persons.
104. The sight of a dead person is horrifying to me.
105. I always know what to say to a grieving person.
106. I often seek advice from others.
107. It does not bother me when people talk about death.
108. I cannot remember a time when my parents were angry with me.
109. I do not think people in today's society know how to react to a person who is grieving.
110. I never have an emotional reaction at funerals.

111. I often think about how short life is.
112. I am not afraid of dying from cancer.
113. I do not mind going to the doctor for check-ups.
114. I shudder at the thought of nuclear war.
115. The idea of dying holds no fears for me.
116. I never lose my temper.
117. I have always been completely sure I would be successful when I tried something for the first time.
118. I am not usually happy.
119. I feel that the future holds little for me to fear.
120. I cannot ever remember feeling ill at ease in a social situation.

121. I find myself sighing more now than before the death.
122. I spent a great deal of time with the deceased before the death.
123. I find that comforting others helps me.
124. My family seems close to me.
125. I feel that I did all that could have been done for the deceased.
126. My religious faith is a source of inner strength and comfort.
127. I am smoking more these days.
128. I am not a realistic person.
129. I am awake most of the night.
130. I feel exhausted when I go to bed but lie awake for several hours.

131. I lose sleep over worry.
132. I often wake in the middle of the night and cannot get back to sleep.
133. I sleep well most nights.
134. Things seem blackest when I am awake in the middle of the night.
135. I can sleep during the day but not at night.

THE GRIEF EXPERIENCE INVENTORY ANSWER SHEET

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NAME ______________________ SEX: M ____ F ____ AGE ____ DATE ____________

ADDRESS ______________________ OTHER INFORMATION ______________________

CITY & STATE ______________ ZIP __________ ______________________

OCCUPATION ______________________ ______________________

____

DIRECTIONS: Blacken in the boxes under T (True) or F (False) to show your response to each question in the booklet.

Be careful to see that the number you mark is the same as the number of the question you are answering.

T — TRUE F — FALSE

T F
1 ☐ ☐
2 ☐ ☐
3 ☐ ☐
4 ☐ ☐
5 ☐ ☐

T F
6 ☐ ☐
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Den	AR	SD	Des	AH	Gu	SI	LC	Ru	DR	Som	DA

Appendix 6

Demographic details of participants

Patient ID____________________

Bereavement study

Personal details

1 Study (B or C) ____________________

2 Surname ____________________

3 First name ____________________

4 Address ____________________
____
____
____

5 Telephone number ____________________

6 Date of Birth ____________________

7 Gender Male / Female

8 Age ____________________

9 Date of death of partner/spouse (or name for control) ____________________

10 Cause of death ____________________

11 Was this loss sudden and unexpected Yes / No

12 Length of terminal illness (if appropriate) ______(days) _______(weeks) _____(Months)

13 Ethnic group (census) ____________________

14 Religious/cultural beliefs ____________________

15 Do you attend religious worship Yes No

16 About how many times a month did you go in the year before your loss ? ____________________

17 How many times a month do you go now? ____________________

18 Do you have any children Yes / No

19 If yes how many live at home ______________

20(a) If living away how often do you see your children? ____ week _____ month _____ year

20(b) If living away do you speak by telephone? Yes / No

20(c) If yes how often? daily weekly monthly quarterly yearly

Patient ID____

Demographic

21 What type of accommodation do you live in

Flat Bungalow House Other

22 Who owns your home?

Rented Council Own Other

23 Highest level of academic achievement

None O level A-Level Diploma Degree Postgraduate degree
[or equivalent]

24 Employment status ______________________________

25 Current/last/highest paid job

Health information

26 Do you use tobacco? e.g. smoke / take snuff / chew tobacco Yes / No

27 If you smoke what is it cigarettes/ pipe / cigars

28 If you use another tobacco product what is it and how much do you use ________________

29 If you smoke how many do you smoke a day __________

30 How much did you smoke / use in the year before your loss ____________More / less

31 Do you drink alcohol Yes / No

32 If yes how many units do you drink per week ________________

33 How much did you drink before your loss ________________

34 In the year before your loss how many days off work did you take due to sickness ________

*** 35 Jarman Index Score ______________________________

36 Please could you tell me any medication that you used regularly (say more than once a month) that your doctor has prescribed in the year before your loss.

Patient ID ____

Financial

37 In the year before your loss about how money did you have per week to spend on luxury items

38 In the year before your loss did you feel financially secure Yes / No

Previous bereavement

39 Have you ever been bereaved before Yes / No

Was this bereavement the loss of any of the following people
Mother, Father, Brother, Sister, son, daughter, Husband, wife, partner, close friend.

If yes could you give some of the following details about each one:

A What was the relationship of the deceased to you

How long ago was it

How much did this loss affect you..

No impact (0)	Slightly upset (1)	Moderately upset (2)	Quite a bit upset (3)	Extremely upset (4)

B What was the relationship of the deceased to you

How long ago was it

How much did this loss affect you..

C What was the relationship of the deceased to you

How long ago was it

How much did this loss affect you..

D What was the relationship of the deceased to you

How long ago was it

How much did this loss affect you..

What was the relationship of the deceased to you

How long ago was it

How much did this loss affect you..

Appendix 7

Helpfulness questionnaire

Patient identification: ....

Helpfulness of bereavement care from the Primary care Team

1 After your loss did your GP send a letter of condolence?
Yes
No
Don't remember

If yes please would you put a cross in the box that describes how useful you found this letter .

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

2 After your loss did your doctor visit you at your home?
Yes
No
Don't remember

If yes please would you put a cross in the box that describes how useful you found this visit .

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

3 After your loss did your doctor ask you to make an appointment to seen them ?
Yes
No
Don't remember

If you visited your GP please would you put a cross in the box that describes how useful you found this visit .

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

Patient identification: ....

4 After your loss did any other health professionals visit you at your home?
(e.g. District nurse, Psychiatric Nurse, Counsellor, Health visitor, Practice Nurse, Other)

Yes
No
Don't remember

If yes please would you write down the type of health professional that visited and put a cross in the box that describes how useful you found this visit .

Type of health professional..

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

Type of health professional..

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

Type of health professional..

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

5 After your loss did anyone from your GP surgery provide you with written/verbal information about the sort of emotions and feelings you would have following your loss?
For example a booklet describing the normal feelings of grief.

Yes
No
Don't remember

If yes who provided this to you ? ....

What did they provide? ....

How useful was it?

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

6 After your loss did anyone from your GP surgery provide you with written/verbal information about what to do following the death of someone?
For example a booklet explaining how to register a persons death.

Yes
No
Don't remember

If yes who provided this to you ? ....

What did they provide? ....

How useful was it?

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

7 After your loss did anyone from your GP surgery provide you with written/verbal information about services or organisations available to bereaved people?
For example information about bereavement counsellors, or organisations such as Cruse.

Yes
No
Don't remember

If yes who provided this to you ? ....

What did they provide? ....

How useful was it?

No help at all	A little Help	Helpful	Very helpful	Extremely helpful

8 Answer this question only if you answered YES to questions 2, 3 or 4.

Did you receive a follow-up visit from your doctor or someone from the practice sometime after their initial visit (or appointment)

Yes
No
Don't remember

Who visited?..

How long after the first visit was it?...

If yes how helpful was this for you (please put a tick in the box that most applies)

No help at all	Slightly helpful	Moderately helpful	Quite helpful	Extremely helpful

9 Did you receive any other support from your doctor or the practice?

Yes
No
Don't remember

If yes please describe...

....

....

10 Overall how would you rate the support you received from your GP at the time of your loss?

Poor	Fair	Good	Very good	Excellent

11 In your own words could you write down the main things that you felt were particularly good about the service you received from your GP and the practice

12 In your own words could you write down what you felt was particularly poor about the service you received from your GP and the practice.

13 So that we can improve the services offered to bereaved people, can you suggest anything that would improve the service that doctors and health professionals could do to help people when they have suffered the loss of a spouse or partner?

Thank you for your help in completing this questionnaire

Appendix 8

GP questionnaire

Bereavement research in Primary Medical Care.

The following questions are designed to find out the sort of care / services that you provide to bereaved patients and forms part of the bereavement research being carried out by Professor Tony Kendrick and Jon Birtwistle of the University Department of Primary Medical Care at Southampton University.

At present there are mixed views on the role of GPs in the care of bereaved people. Unfortunately little is known about what GPs actually do in practice and the impact that this has on patient well-being.

This questionnaire is designed to find out general information about bereavement care and specific information about the care actually care provided to your patient (...) who consented to participate in our study.

A. Demographic details

1. GP ID ....

2. Are you a principal / non-principal?

3. Are you full time / ½ part time / ¾ part time other..............? please specify

4. What is your age? ....

5. What is your gender? male / female

6. How many doctors are there in your practice who are: full time? ....
   ½ part time? ....
   ¾ part time?.............
   other?.......................Please specify

7. How many patients are there in the practice? ....

8. Do you operate a shared or personal list system? Shared / Personal

9. How many patients have you on your list? .... (if you have a personal list)

B. Bereavement general

1. Have you a particular interest in bereavement care? (more than the average GP) Yes / No

2. Have you a particular interest in palliative care? Yes / No

3. Have you ever been on a training course about bereavement? Yes/No

4. Are you a member of any groups linked with bereavement care or research ? (e.g. Bereavement Research Forum) Yes / No

C. **Bereavement care belief**

Please read the following statements and indicate your views about bereavement care by ticking the box that is closest to your views.

1. I feel that GP bereavement visits should be part of a GP's routine work

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

2. I feel that visiting newly bereaved patients is intrusive on their grief

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

3. I feel that GPs should initiate contact with newly bereaved patients (e.g. through visits, letter or phone calls).

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

D. **General information**

Does your practice do any of the following?

1. Keep a death register? (a written list or computerised) Yes / No

2. Notify the practice team of deaths? Yes / No

3. If so how do you do this? ....

4. Routinely record patient deaths in the notes of spouses / partners ? Yes / No

5. Provide training in how staff should deal with bereaved patients? Yes / No

6. If so please specify..

Which members of staff have undergone training (please tick)

Doctors	
Practice Nurse	
District Nurse	
Health Visitors	
Receptionists	
Others (please name)	

7. Does the practice have links with any bereavement services? Yes / No

If so please specify..

....

8. Does the practice provide the services of a professional Psychologist / counsellor who can deal with bereaved patients?

Yes / No

E. **Specific Information regarding care provided to**

Name of patient: ....

1. Where you already in contact with the bereaved person prior to the death? Yes / No

2. If not how did you find out that the above patient had been bereaved?

....

3. How long after the spouse / partner death was it before you knew of the loss?

Immediately ....Hours ....days ....weeks ....months

Once you knew that the above patient had been bereaved:

4. Did you / someone else from the practice send a letter of condolence to the home of the bereaved?

Yes ☐
No ☐

5. Did you yourself visit the bereaved patient at home soon after death?

Yes ☐
No ☐

If yes, how long after the death was this (in days)...................................days

6. Did another member of the Primary Care team visit the bereaved soon after the death?

Yes ☐
No ☐
Don't know ☐

If yes, how long after the death was this (in days)...................................days

7. Did you make, or invite the bereaved to make, an appointment to see you soon after the death?

Yes ☐
No ☐
Don't remember ☐

If yes, how long after the death was this (in days)...................................days

8. If you visited or saw the bereaved patient soon after the loss did you assess them for any of the following? (please tick if assessed)

General physical health	
Depression	
Anxiety	
Sleep disorders	
Suicidal thoughts	
Loneliness	
Ability to cope alone	

9. If you visited or saw the bereaved patient soon after the loss did you prescribe any medication to help them cope with a grief related problem?

Yes ☐
No ☐

If yes please could you name the medication and reason for prescribing this.

Medication prescribed	**Reason**

10. Did you / other health professional provide the bereaved patient with written/verbal information about the sort of emotions and feelings they may experience when mourning? (For example a booklet describing the normal feelings of grief.)

Yes ☐
No ☐

If yes who did this...

What was it..

11. Did you / the practice provide the bereaved patient with any written/verbal information about services or organisations available to bereaved people?
For example information about bereavement counsellors, or organisations such as Cruse.

Yes ☐
No ☐

If yes who did this...

What was it.. .

12. Did you / the practice provide the bereaved patient with written/verbal information about what to do following the death of someone?
For example a booklet explaining how to register a persons death.

Yes ☐
No ☐

If yes who did this...

What was it..

13. If you saw the bereaved patient soon after the bereavement (home visit or appointment at the practice) did you arrange a follow-up visit.

Yes ☐
No ☐

Who visited?...

How long after the first visit was it?..............months ....weeks ....days

14. Did you refer the bereaved patient to any of the following? (please tick if referred)

Practice counsellor ☐

Other Counsellor ☐

Psychiatric services . ☐

Psychologist ☐

Spiritual care giver (e.g clergy) ☐

Cruse ☐

Bereavement support ☐

Social worker ☐

15. Did you or a representative from the practice attend the funeral ?

Yes ☐
No ☐

If so who?..

16. If you / the practice provided any other support not mentioned elsewhere please would you describe what was provided in the space provided below.

17. Do you have any other comments on the care provided to the bereaved patient?

Thank you for agreeing to help with this research.

Appendix 9

Post interview questionnaire

Post Interview Questionnaire

1 **Did you feel that you were able to cope with the length of the interview?**

Yes, quite easily ☐

Only just ☐

No ☐

2 **Did you find talking to Jon in the interview helpful?**

Yes, very helpful ☐

Yes, a little ☐

No ☐

3 **Did you feel the interview caused you distress?**

Yes, a lot ☐

A little ☐

No ☐

4 **Did you feel that Jon was understanding during the interview?**

Yes, very understanding ☐

Yes, a little ☐

No ☐

5 **Did you find it easy to talk to Jon during the interview?**

Yes, very easy ☐

Difficult at times ☐

Extremely difficult ☐

If you have any other comments please write below and on the back page if necessary:

Thank you for completing the questionnaire

(LREC Southampton South and West number: 260/99)

Appendix 10

Letter to GP

Re: **Bereavement research in Primary Medical Care**
(LREC Number...)

Dear Dr.,

We write to ask for your help with a research project to find the best ways that doctors can help bereaved people. This research will be carried out by Jon Birtwistle, a Nurse experienced in mental health research and was approved by the Local Research Ethics Committee Southampton South and West on ______1999

We wish to recruit two bereaved patients from your patient list. These patients must be between 50 to 75 year old that have lost a spouse or partner. They would be interviewed twice at 3 months and 13 months post bereavement. For each patient we would also recruit a married/partner control patient who would be interviewed once only. With your and the patient's permission we would like access to their medical notes.

What this involves for you

Your help is required to identify patients, give consent for them to be contacted and for Jon to have access to their notes, and to reflect on care of bereaved patients by completing a brief (5-10 minute) questionnaire at three months post bereavement.

Help from practice administrative staff will be required to post a pre-printed standard letter and consent form to bereaved and control patients. This avoids 'cold' contact by Jon and maintains patient confidentiality.

We would be most grateful if you would help us with this research as it will identify key issues related to good outcome in bereaved adults and inform Primary Care Teams about the effectiveness of practice.

We attach a form and pre-paid envelope for you to return indicating whether you would be interested. The form contains a tick box for you to obtain further information.

If you would like to find out further details about the research please phone Jon Birtwistle or Tony Kendrick on 01703 241050.

Yours sincerely,

Tony Kendrick
General Practitioner and
Professor of Primary Care

Jon Birtwistle
Research Nurse

Bereavement research in Primary Medical Care

From Dr. XXX

Address

Tel number

Fax

Email

I am / am not * interested in helping with this research.
(*Please delete as appropriate)

Please indicate the best days and times to contact you regarding the study on the box below.

	Mon	Tues	wed	Thurs	Fri
0800-0900					
0900-1000					
1000-1100					
1100-1200					
1200-1300					
1300-1400					
1400-1500					
1500-1600					
1600-1700					
1700-1800					

Other days / times :

I would like you to send me a copy of the following:

Further information re: the Study	**Please tick if required**
Protocol	
Preprinted patient letter and consent form	
GP consent form	
Patient questionnaires to be used	
Demographic information sheet	

Please return in the attached pre-paid envelope.

Thank you for your help.

Bereavement research in Primary Medical Care

Consent form from GP

I Dr…………………………………………………………………………(Print full name)

have read and understood what is involved in this study.

I have sent details of this study to the following patient:

(Patients name)…………………………………………………………………………

who has consented to be contacted by Jon Birtwistle regarding the bereavement research being carried out by the University of Southampton Department of Primary Medical Care.

I therefore give permission for Jon Birtwistle to contact the above patient and to have access to their medical notes for the purpose of this study.

Signed…………………………………………………………………………

Date…………………………………………………………………………

Appendix 11

Letter to bereaved people

Re: Research to examine General Practice care for those bereaved

Dear

We are carrying out research to find out the best way that doctors can help people who have been bereaved. Your doctor has agreed to help us with our research by sending out this letter to people like yourself who have recently experienced the loss of a spouse or partner.

However, we would like to reassure you that neither your name or address or any personal information has been given to us by your doctor. This letter was sent directly by your doctor and not by ourselves.

Who will carry out the research?

This research is being carried out by Jon Birtwistle a Research Nurse at the Department of Primary Medical Care, University of Southampton. He has no connections with your practice.

How will the research be carried out?

Jon would interview people who have been bereaved in the last three months to find out what sort of problems they have experienced. Jon would also like to repeat the interview in about a year's time to see how things had changed. Jon would ask you about yourself, the circumstances of your loss, the social support that you have and ask you to complete a number of short questionnaires designed to measure your health. He would also ask you about the support you have received from your doctor and the practice.

He would also record some information from your medical records such as the number of times you have seen your doctor over the last year, the type of medication you take and any problems you may have had in the past. This information would be treated confidentially and only used for this research. Your doctor will only allow access to your medical notes if you give your consent.

How long will the interview last?

The interview would last about one hour and would usually take place in your home at a convenient time and day. It could take place in your doctor's surgery if you prefer.

All information would be confidential.

(LREC Southampton South and West number: 260/99)

Will it be upsetting?

Asking questions about the loss of a loved one can be upsetting for some people. You can stop at any time during the interview. Please do not feel there will be any pressure to continue if you do not want to.

Please feel free to have someone sit with you during the interview if you want to.

At the interview you will be given some contact 'phone numbers that you could call if you needed to talk to someone for support. You could also speak with your doctor who will be aware that you have taken part in the study.

How can you help?

If you would like to help with this research please read through the consent form and fill out your contact details (name, address and telephone number) then sign and date it. Return the consent form in the free-post envelope provided. **You do not need a stamp**. Jon will then contact you in the next few days to arrange a visit.

If you would like to find out further details about the research before you consent please phone Jon or Professor Kendrick at the Department on 01703 241050.
All calls will be treated in the strictest confidence

What if you don't want to take part?

It is perfectly all right not to take part. It will make no difference to the care that you receive. You will also remain anonymous to ourselves.

Thank you for reading this and considering your reply.

Yours sincerely,

Jon Birtwistle
Research Nurse

Professor Tony Kendrick
Head of Department

(LREC Southampton South and West number: 260/99)

Consent form

I ....(Print full name)

have read and understood what is involved in this study. I agree that Jon Birtwistle can contact me regarding this study using the details I have given below. I also give permission for him to have access to my medical notes for the purpose of this study.

I understand that I can withdraw at any time from this study without it affecting my future care.

Signed..

Date..

Contact details

This information is so that we can contact you for the study. Please remember that this information will be dealt with in absolute confidence.

Your address ....

....

....

....

....

Your telephone number:...

(LREC Southampton South and West number: 260/99)

Appendix 12

Letter to FD & FD letter to bereaved people

Dear Sir or Madam,

Care of the bereaved in the community. A research study.

As you know, following the death of a spouse or partner many people suffer from worsening physical and mental health, and yet may not ask for help from their professional carers.

We are piloting a research project to assess bereavement care by GPs and District / Community Nurses in the community and would be grateful if you could offer advice about approaching bereaved people for the study. This study was approved by the Southampton Local Medical Research Ethics Committee on 24th September 1999.

For the pilot study we wish to contact and interview people aged between 50 and 75 years, who have lost a spouse or partner and we aim to interview them between three months up to a year following bereavement. Our research will be carried out by Jon Birtwistle, a fully qualified nurse experienced in mental and physical health research.

To date we have attempted to approach bereaved people via their GP which has proved to be difficult, because GPs deal with them only infrequently. However, an alternative method would be to approach bereaved people via Funeral Directors. If this method of approach was acceptable each Funeral Director would be asked to identify clients who fulfilled our selection criteria and to post a pre-printed standard letter and consent form to the bereaved person, to inform them of our study and ask them to consider taking part. We enclose copies of a draft letter and consent form.

This approach avoids 'cold' contact by ourselves and maintains confidentiality, as we would have no information about the bereaved person unless they responded and gave consent to be contacted.

We believe Funeral Directors have a good deal of experience relevant to our project and are in a good position to help identify people who may suffer worsening health following bereavement.

We would be most interested to know your opinion on this matter and therefore Jon will telephone you in about a weeks time, hopefully to discuss it further with you.

Thanks in anticipation,

Yours sincerely,

Tony Kendrick BSc MD FRCGP General Practitioner Hill Lane Surgery and Professor of Primary Care	Jon Birtwistle MSc RGN Research Nurse

(LREC Southampton South and West number: 260/99)

Re: Research to examine General Practice care for those bereaved

Dear

We are carrying out research to find out the best way that doctors can help people who have been bereaved.

So that we can contact a number of people like yourself we have asked a small selection of Funeral Directors to help us with our research by sending out this letter to people who have recently lost a spouse or partner. However, we would like to reassure you that neither your name or address or any personal information has been given to us by anyone. This letter was sent directly by the Funeral Directors and not by ourselves. We would also add that we have not told your doctor about this study.

Who will carry out the research?

This research is being carried out by Jon Birtwistle a Research Nurse at the Department of Primary Medical Care, University of Southampton. He has no connections with your practice.

How will the research be carried out?

Jon would interview people who have been bereaved in the last three months to find out what sort of problems they have experienced. Jon would also like to repeat the interview in about a year's time to see how things had changed. Jon would ask you about yourself, the circumstances of your loss, the social support that you have and ask you to complete a number of short questionnaires designed to measure your health. He would also ask you about the support you have received from your doctor and the practice.

We would also like to have permission from yourself and your doctor to record some information from your medical records such as the number of times you have seen your doctor over the last year, the type of medication you take and any problems you may have had in the past. This information would be treated confidentially and only used for this research. Your doctor will only allow access to your medical notes if you give your consent.

How long will the interview last?

The interview would last about one hour and would usually take place in your home at a convenient time and day.

All information would be confidential.

(LREC Southampton South and West number: 260/99)

Will it be upsetting?

Asking questions about the loss of a loved one can be upsetting for some people. You can stop at any time during the interview. Please do not feel there will be any pressure to continue if you do not want to.

Please feel free to have someone sit with you during the interview if you want to.

At the interview you will be given some contact 'phone numbers that you could call if you needed to talk to someone for support. You could also speak with your doctor who we would make aware that you have consented to take part in the study.

How can you help?

If you would like to help with this research please read through the consent form and fill out your contact details (name, address and telephone number) then sign and date it. Return the consent form in the free-post envelope provided. **You do not need a stamp**. Jon will then contact you in the next few days to arrange a visit.

If you would like to find out further details about the research before you consent please phone Jon or Professor Kendrick at the Department on 01703 241050.
All calls will be treated in the strictest confidence

What if you don't want to take part?

It is perfectly all right not to take part. It will make no difference to the care that you receive. You will also remain anonymous to ourselves.

Thank you for reading this and considering your reply.

Yours sincerely,

Jon Birtwistle Research Nurse	Professor Tony Kendrick Head of Department

(LREC Southampton South and West number: 260/99)

Consent form

I ....(Print full name)

have read and understood what is involved in this study. I agree that Jon Birtwistle can contact me regarding this study using the details I have given below. I also give permission for him to have access to my medical notes for the purpose of this study.

I understand that I can withdraw at any time from this study without it affecting my future care.

Signed..

Date...

Contact details

This information is so that we can contact you for the study. Please remember that this information will be dealt with in absolute confidence.

Your address ....

....

....

....

....

Your telephone number:...

(LREC Southampton South and West number: 260/99)

Appendix 13

DN letter and questionnaire

**University
of Southampton**

**School of Medicine
Department of Primary
Medical Care**

*Primary Medical Care
University of Southampton
Aldermoor Health Centre
Aldermoor Close
Southampton SO16 5ST
United Kingdom*

*Tel +44 023 8024 1065
Fax +44 023 8070 1125
Email clg@soton.ac.uk*

Dear Colleague,

An investigation of the role of the Community / District Nurse in the care and support of bereaved patients.

I write to ask for your help with a research project to examine the role of the Community / District Nurse service in the care and support of those bereaved.

I am a Nurse working at the University of Southampton, Department of Primary Care carrying out research to look at the role of health professional in the care and support of people who have been bereaved.

At present there is little information on the range of health and social problems in those bereaved and on the effectiveness of care and support provided. Health professional are split over whether primary care support for bereaved patients should be proactive or reactive, and are unclear where primary care services should concentrate scarce resources.

Because District Nurse's provide care to patients in the community they are ideally placed to identify the health and social needs of those bereaved. It is therefore important that the experience and opinion of the Community / District Nurse is taken into consideration. I would therefore be most grateful if you would complete the enclosed questionnaire and **return it to me in the attached free post envelope**. The average time taken to complete this questionnaire is about 7 minutes.

The questionnaire is designed to find out the range of nursing practice, views and beliefs from a representative sample of Community / District Nurses in the United Kingdom. I have put a numerical code on each questionnaire so that I can identify particular areas of the country to allow statistical comparisons. It will not enable me to identify individuals, and all answers will be anonymised and treated in the strictest confidence. The questions are not designed to be judgmental in anyway and there are no right or wrong answers.

Should you have any queries or suggestions please do not hesitate to contact me on
023 80 241054 or Email jb11@soton.ac.uk

Thanks in anticipation,

Yours sincerely,

Jon Birtwistle RGN, BSc (Hons), MSc
Research Nurse

Area code: ___________

Bereavement Research in Primary Health Care

Please read all of the following questions carefully. All your answers will be anonymised and treated in the strictest confidence. Please remember they are not designed to be judgmental in anyway and should reflect your actual nursing practice, personal views and beliefs. Your views are important.
Thank you for your help.

A. Bereavement general

1. Have you a special interest in bereavement care? Yes / No

2. Have you a special interest in palliative care? Yes / No

3. Other than in your basic training, have you ever attended a training course about bereavement? Yes/No

4. How well informed do you feel about bereavement issues?

☐ Very well informed

☐ Well informed

☐ Informed

☐ Poorly informed

☐ Very poorly informed

5. Who do you think should be responsible for keeping you informed about bereavement issues?

Yourself ☐ Your employer ☐ Both yourself and employer ☐

6. Which of the following best describes your education about bereavement?
(Please tick all that apply)

☐ None

☐ Pre registration

☐ Post registration lectures / seminars / workshops

☐ Read nursing / medical literature

☐ Open learning

☐ Formal qualifications

☐ On the job

☐ Public education such as television programmes, news media

☐ Internet

☐ Other, please specify ________________________________

7. Are you a member of any groups linked with

Area code: ___________

bereavement care or bereavement research ?
(e.g. Bereavement Research Forum, CRUSE) Yes / No

Other? (please specify)____

B. **The role of the Community / District Nurse.**

Please read the following statements and indicate your views about bereavement care by **ticking the box** that is closest to your views.

1. I feel that bereavement visits to relatives of those patients **who were on my caseload prior to their death** should be part of my routine work as a Community /District Nurse.

Strongly Agree	Agree	Uncertain	Disagree	Strongly disagree

2. I feel that bereavement visits to relatives of patients **other than those who were on my caseload prior to their death** should be part of my routine work as a Community /District Nurse (e.g. the suddenly bereaved, who are patients at the practice).

Strongly Agree	Agree	Uncertain	Disagree	Strongly disagree

3. I feel that visiting newly bereaved patients is intrusive on their grief

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

4. I feel that District Nurses should initiate contact with newly bereaved patients (e.g. through visits, letter or phone calls) **who were not on the caseload** to ensure they are coping.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

5. I feel that District Nurses should maintain contact with newly bereaved patients (e.g. through visits, phone calls) **who were on the caseload.**

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

6. If you feel that District Nurses should maintain contact with newly bereaved patients how long do you believe this should be for? (**Please write in number of weeks / months**)

____

Area code: ___________

7. I feel that District Nurses have an important role to play in helping bereaved patients to come to terms with their grief.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

8. I feel that bereavement care is the role of the GP.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

9. I feel that bereavement is best dealt with by the family and not a health professional

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

10. I feel that I have received sufficient training in dealing with newly bereaved patients.

Strongly agree	Agree	Uncertain	Disagree	Strongly disagree

11. As a Community / District Nurse the majority of bereaved people I see are aged:

Less than 50	50-55	56-60	61-65	66-70	71-75	76-80	81-85	85+

Area code: ___________

C. General information

Does your practice do any of the following? (please circle)

1. Keep a death register? (a written list or computerised) Yes / No / Don't know

2. Share information about deaths with the whole primary care team? Yes / No / Don't know

   If so how does the practice do this?
   (e.g. meetings, message book) ....

3 Have a policy for identifying bereaved relatives after a Patient's death? (any bereaved patients within the practice list) Yes / No / Don't know

4. Routinely record patient deaths in the notes of spouses / partners registered in the practice? Yes / No / Don't know

5. Provide training in how staff should deal with bereaved patients? Yes / No / Don't know

   If so please specify..

6. Does the practice have specific links with any bereavement services? Yes / No / Don't know

   If so please specify..

   ....

7. Does the practice provide the services of a professional Psychologist / Counsellor who can deal specifically with patients who have been bereaved?

   Yes / No / Don't know

8. **Does your employing trust do any of the following? (please circle)**

   Provide training in how staff should deal with bereaved patients?

   Yes / No / Don't know

   If so please specify..

Area code: ___________

D. Specific Information regarding care provided to bereaved patients at the practice

1. Please tick which best describes the bereavement care offered by your practice to spouses / partners:

Every bereaved patient at the practice is routinely offered contact with a member of the Primary Health Care Team?	
No bereaved patients are routinely offered contact with a member of the Primary Health Care Team?	
Bereavement contact is **only offered** when a member of the practice has been involved in the care of person who died.	
Bereavement contact is **only offered** when it is requested by the spouse / partner.	

2. Do you yourself visit the bereaved patient at home soon after death?

Yes always ☐ Yes frequently ☐
Yes occasionally ☐ No ☐

Ideally, how long after a person has died should you perform a routine bereavement visit?

...................................days

3. Do other members of the Primary Care team normally visit the bereaved soon after the death?

Yes ☐
No ☐
Don't know ☐

If yes who ....

And how long after the death is this normally (in days)..................................days

4. If you visit or see the bereaved patient soon after the loss do you normally assess* them for any of the following? (please tick any assessed).

*An assessment is defined as talking or asking specific questions about the particular problem with the bereaved or a close relative / friend or using an assessment tool to measure any problems.

General physical health	
Depression	
Anxiety	
Sleep disorders	
Suicidal thoughts	
Loneliness	
Ability to cope alone	
Other	

Area code: ___________

5. Do you / other health professionals provide the bereaved person with written/verbal information about the sort of emotions and feelings they may experience when mourning? (For example a booklet describing the normal feelings of grief.)

Yes ☐

No ☐

Don't know ☐

If yes, who normally does this?...

What information is provided?...

6. Do you / the practice provide the bereaved patient with any written/verbal information about services or organisations available to bereaved people?
(For example information about bereavement counsellors, or organisations such as Cruse.)

Yes ☐

No ☐

Don't know ☐

If yes who normally does this...

What is it.. .

7. Do you / the practice provide the bereaved patient with written/verbal information about what to do following the death of someone?
For example a booklet explaining how to register a person's death.

Yes ☐

No ☐

Don't know ☐

If yes who normally does this?...

What information is provided?...

8. If you see the bereaved patient soon after the bereavement (home visit) do you normally arrange a follow-up visit?

Yes ☐

No ☐

Sometimes ☐

Don't know ☐

How long after the first visit would this normally be? ....days ....weeks ....months

9. Would you or a representative from the practice normally attend the funeral ?

Area code: ___________

Yes usually ☐

Yes sometimes ☐

No ☐

Don't know ☐

If yes, who?..

10. Do you ever help the bereaved with any of the following ? :

Arranging the funeral	Yes ☐	No ☐
Budgeting their finances	Yes ☐	No ☐

11 If you / the practice provide any other support not mentioned elsewhere please would you describe what this is in the space provided below.

12. Do you run / or assist in running a bereavement support group Yes / No

13. Do you have any other comments on the care provided to the bereaved patient?

Area code: ___________

Please would you answer the following questions about yourself. These issues might be relevant to the way you view bereavement. This is confidential and the data will not be used to identify any individual. It will be pooled along with data from other district nurses. Please tick the box or circle the answer as appropriate.

1. Are you male ☐ female ☐

2. What is your age category?

20 – 25	
26 – 30	
31 – 35	
36 – 40	
41 – 45	
46 – 50	
51 – 55	
56 – 60	
61+	

3. What is your marital status?

Single	
Married	
Living with partner	
Separated	
Divorced	
Widowed	

4 What is your spiritual affiliation

No spiritual affiliation	
Christian	
Jewish	
Hindu	
Muslim	
Sikh	
Private, personal spirituality	
Other, please specify	

5. Are you employed full time / part time / other?

Please specify____

6. Have you ever suffered a significant bereavement yourself ? Yes / No

7. If the answer to (6) was yes. Has your personal loss effected the way you support and care for your bereaved patients? Yes / No

In your own words please could you describe the in what way.

____

____

____

____

Area code: ___________

8. Please mark any of the following courses that you have completed:

Enrolled Nurse (EN)	
Registered Nurse (RN)	
Specialist diploma in Community /District Nursing	
Specialist degree in Community /District Nursing	
Registered Nurse project 2000 diploma	
Diploma in nursing	
Degree course (any discipline)	
Masters course (any discipline)	
MPhil/PhD	
Nurse teacher course	

9. Which best describes your present position?

Staff nurse	
Senior staff nurse	
Sister / charge nurse	
Nurse specialist	
Other, please specify	

Other_______________________________________

10. In what year did you qualify as a nurse? ______________________

11. In what year did you qualify as a District Nurse? ______________________

12. How long have you been a District Nurse? ___________years

13. How long have you been in your current post? ___________years

14. How many patients have you on your caseload? ___________

15. How many visits would you normally make in an average week? ___________

Thank you for agreeing to help with this research.

Please return your questionnaire in the pre-paid envelope

Appendix 14

Interview schedule with DNs

Questions for semi-structured district nurse interviews

1 Bereavement follow-up

What do you usually do when one of your patients die?

When would you follow up a bereaved person?

What do you do in a bereavement follow-up?

When would you not follow up a bereaved person?

What would happen if you didn't go?

Is time a factor in your decisions?

In any bereavement follow-up what guides your decisions:

- Guidelines (practice policies, national guidelines, others)
- Motivated for yourself? Do your feel a need to follow up?
- Motivated for your patient
- Do you have a sense of empathy or sympathy?
- Do you have a sense of religious duty?
- Do you believe its useful?
- Do your own personal bereavements effect your practice?

2 Closure

When you follow up a bereaved person how do you decide to finish making visits?

How difficult do you find it (the act of closure)?

Are there people who you still keep in contact with? Why do you keep in contact with them as appose to others.

3 Personal and professional boundaries

Do you experience a sense of loss yourself?

Have you ever experienced a sense of personal vulnerability?

How do you gain support (practice meetings, supervision, colleagues, family,)?

Do you attend the funerals of your patients? When would you attend and when not?

How do you manage your professional and personal boundaries when dealing with bereaved people?

How important is a sense of professional boundary between the bereaved person and yourself?

Does bereavement follow-up visiting fulfil any needs in yourself?

Have you ever met with the bereaved people within your own time?

4 Bereavement general

What do you know about bereavement?

Are there aspects of bereavement that you're not sure about

What are your skills in bereavement support?

What is your training in bereavement support (counselling etc)?

What are your experiences of bereavement?

Appendix 15

Consent form for DNs

Consent form for taped interview

I ……………………………………………………………(Print full name)

have read and understood what is involved in this study and give permission for Jon Birtwistle to carry out an audio-taped interview with me for the purpose of this study.

I understand that:

the interview will be tape recorded, transcribed and analysed.

the tape(s) and transcription will be anonymised so that I cannot be identified from any references made during the interview to names, dates or places.

the tape(s) and transcription will be kept in a safe locked place for the duration of the study and then destroyed.

the tape(s) and transcription may be heard or read by an academic supervisor to Jon Birtwistle (Professor Sheila Payne, a Psychologist, or Professor Tony Kendrick, a General Practitioner) and that this will be done in the strictest confidence and be used solely for the purpose of academic supervision.

Jon Birtwistle may quote some sections of the interview for the purpose of this research and any academic publications, but that this will be anonymised so that I can not be identified from any references made during the interview to names, dates or places.

I also understand that I can withdraw at any time from this study.

Signed ……………………………………………………………………………..

Date ……………………………………………………………………………

Appendix 16

Thematic framework (9 themes)

Thematic index for District Nurse Interviews

1 Relationship with bereaved family

a. Relationship with family prior to bereavement (e.g. Involvement with the care of the patient)
b. Contact as early as possible

c. No prior contact with family until bereavement

2 Influence on DN support

a. Time (Lack of time)
b. Intuition
c. Knowledge of the family / Network of support
d. Policies / procedures / guidelines
e. Empathy
f. Protocol developed by practice
g. Professional duty / part of DN role
h. Religious or spiritual beliefs
i. Individual differences / Negotiate with patient
j. Personal experience of bereavement

3 Assessment of bereaved persons needs

a. Self care (washing, dressing, household tasks)
b. Eating
c. Sleeping
d. Mood
e. Help with things (e.g. funeral)
f. Abnormal grief
g. Health problems in bereavement
h. Bereaved person ignoring own health problems

Coping with bereavement

i. Going out / reintegration
j. Feeling happy
k. Getting on with life
l. Missing DNs company
m. Loneliness / isolation
n. Skills (e.g. cooking / driving)

4 Support for DNs

a. Team
b. Family
c. Clinical supervision
d. GPs
e. Other support

5 Professional and personal boundaries

a. Always on duty
b. Visiting in uniforms
c. Friendship
d. Visits in own time
e. Sharing personal information with patients
f. Home number
g. Emotionally involved

Emotional impact

h. Guilt
i. Want to do more
j. Strong emotions (embarrassment, frustration, upset, disgruntled)
k. Job fulfillment / fulfills needs
l. Coping with the stress of the job

Attending funerals

m. Attending funerals
n. Attending funerals in uniform
o. Funerals and relationship with person
p. Act of closure (saying goodbye)
q. Invitations

6 The bereavement visit

Making contact

a. Contact by phone
b. Contact in person
c. Selecting who to follow up
d. Letter / card
e. When out and about
f. Bereaved people contacting DN

Structured visiting pattern

g. Pre funeral visits
h. Post funeral visits
i. Structured timing of visits over time
j. No closure, contact left open / long-term
k. Regular contact
l. Bereaved person refuses contact
m. Closure. End of bereavement visit
n. No follow up

Structured session

o. Informal chat over coffee
p. Structured sessions
q. Provision of information to bereaved people

Practical considerations

r. Time of the visits
s. Practical considerations (bleeps, on call, work load)
t. Collect equipment
u. Documentation of the visit
v. As part of another visit

Impact of the visit

w. Reminder of death (e.g. suffering)
x. Positive impact
y. Provide company / social visit

Other health professionals

z. GP visits
aa. DN communication with GPs about patient health
bb. Bereavement books / contact book
cc. GP and communication with bereaved

DN skills

dd. Listening skills

7 Interest education and knowledge

a. Interest
b. Training in bereavement
c. Personal experience of bereavement
d. DN as supporter or counsellor
e. Grief wheel
f. Stages
g. No models

Training

h. Trust courses
i. Palliative care
j. Pre-registration courses
k. Personal interest
l. On the job
m. Post registration training

8 Resources

a. Cancer death
b. Inequality
c. Changes in society
d. Family networks
e. Small town / close networks
f. GP
g. Counsellor
h. CPN
i. HV
j. Macmillan
k. Church
l. Bereavement groups
m. Other specialists colleagues

9 Case studies and examples

Appendix 17

Chart for theme 4

KEY THEME: Support for district nurses				
Participants	**Sub theme: Team**	**Sub theme: Family**	**Sub theme: Clinical supervision**	**Sub theme: Others**
DN 1	Erhm and I know that I won't as soon as he goes I will walk into the office and they'll be there for me (Page 10) although I haven't really I haven't really ever shown that I've needed their support erhm I'm very sort of erhm too independent almost sometimes I never say I you know I really need you to help me or whatever I try and do all of it (Page 11)			
DN 2	we are quite a close team we talk through things, you know we'll come straight back through that door and say you know "I'm not happy about this" or you know, yes we are all quite stoic and we all get on actually, nobody that I call a very emotional sort of person, no, we're all quite strong (Page 6)	my husband he knows everything, go home and tell him everything, when I've done that I'm better		Yes up's and down, you can have several terminals all at the same time, and then you don't have anything in a month. So we don't get bogged down, do you know, you get a natural break and um (Page 6)
DN 3	I think within the team I am very fortunate we have a very good staff nurse and very good auxiliary nurse and we talk through quite a lot of issues about patients because that is how we are caring for them. I think really probably our supervision as it were comes from each other (Page 6)		We can have access to um clinical supervision from a peer um every four months. Or I suppose if you wanted it, sort of more often than that. But I really think that we are very fortunate in our team, that we support each other and in lots of ways the supervision that we give each other is better because we know what we are talking about. (Page 6)	
DN 4	We talk as a team, um, we support each other and it's mainly within my, (Page 4)	I don't often bring it home although, perhaps once it was beginning to affect me a bit and my husband understood and he was very supportive but usually we just talk to each other at work, mainly within our own team. (Page 4)		
DN 5	Um, I'd say no I don't get supported, um and I don't mean that I am being derogatory of my peers, however I think I, if I did have a problem I would go and say look this is my problem I think, I would be supported, but they don't they don't come out and say how did that one go, or anything like that, it's not sort of recognised (Page 9)	I go to my family and my husband that would support me (Page 10)		I have actually just recently done a course for cruise, I've actually now a bereavement counsellor for cruise, and I have actually used um senarios of patients to to clarify that they are on the right wavelength and I am on the right wavelength, sort of normal, so that I have got a lot of support from them (Page 10) (GPs) they are very up they're very interested in that here, um and they would support me (Page 12)

Participants	Sub theme: Team	Sub theme: Family	Sub theme: Clinical supervision	Sub theme: Others
DN 6	We all meet up at lunchtime every day from all the different practices, we try and see each other at least once in the day and if you have got anything like that that you want to discuss with anyone, you do it then and they are very supportive (Page 6)	Yes yes my husband is in the fire service so he's had to deal with sudden deaths and things like that in his job so he understands that (Page 6)	Um it never comes up at the right time, if you've got somebody terminal like that you haven't got the time to make the appointment for clinical supervision and by the time it does come round you have dealt with it (Page 5)	
DN 7	colleagues quite often, because more often than not they are involved in that particular situation, so they have a huge insight into what is going on, (Page 6)	my poor husband (laughs) he is my main support, but um he is a very good sounding board because he doesn't listen, I know it sounds really funny but he doesn't listen to a word I am saying but it makes me feel better and he can't remember anything I've said the next day (laughs) (Page 6)	we do have clinical supervision and that is quite useful but it's about only, well as often as it needs to, but you know it's never at the time when you may necessarily need it. I mean support is usually incidental you may have done a bereavement visit or had a, a situation you need to discuss and your clinical supervisor may not be able to see you for a couple of weeks or so, so I know it's not a criticism of them, it's just the way the system works so really support comes from colleagues and you know family (Page 7)	
DN 8	We've, I've got a big nursing team here J Right A And we meet on a daily basis so we are always there to talk things through. With terminally ill patients we have two named nurses that go in the majority of the time sort so that the patient and carers are used to one person going in and those two people are also able to offer a lot of verbal support, umm and told they can withdraw at any time if they want to, because sometimes you get situations where you can't possibly go into every day (Page 7)			The GPs here now realise there is a problem, umm because we did mention it to them, because all of the nursing and everything goes on to us, they just tend to abandon us and let us deal with everything and now they are very supportive they will come up on a 1-2-1 and say how are you coping (Page 8)
DN 9	the nursing team and they come back and they have said were you ok and I say ooooh upset, oh no we support each other and that (page 10)		I have been in this area with my boss for a long time and I have (mumbled) there is a couple of District Nurses that I personally know J Yes A Who if I had a problem could go and talk to them but actually if I hadn't I have dealt with it within my own (Page 11)	

Participants	Sub theme: Team	Sub theme: Family	Sub theme: Clinical supervision	Sub theme: Others
DN 10	colleagues, we have got a good team here, we have got a big team, ah and we get a lot of support from our colleagues, umm and yeh I mean quite often they will share that grief with you because they have been involved as well (Page 14)		Clinical supervision You can do that if you wanted to, I have never I have never personally had any felt the need to do that under a bereavement circumstances, but you could do that yes (Page 15)	
DN 11	well, we talk about it amongst ourselves the two of us, we have got clinical supervision, but I have only had it once, umm (Page 11)		Yes, I had it once, and there has been changes recently and we don't want to have to have clinical supervision with the person that we did last time so we are way behind on it, so there is that I suppose (Page 11)	
DN 12	My father died quite suddenly and I couldn't as a nurse do bereavement visits (mobile phone noise) I just couldn't cope, I was in so much grief myself J Stop A Yes, I was in so much grief myself that I as a person couldn't cope with other people's grief. J Mmm A My team were very good and I didn't get too involved with terminally ill patients (Page 9)		we have to have clinical supervision now, ah we can have that whenever we want, but they usually come from the other medical team especially if they (mumbled) usually on the whole, we are usually just as sad as each other (Page 6)	some GPs are very good, umm just being sympathetic (mumbled) really yes (Page 6)

Participants	Sub theme: Team	Sub theme: Family	Sub theme: Clinical supervision	Sub theme: Others
DN 13	but we have been a team, we've (mumbled) we are a very strong, we have bonded very very well together and we all get together at least once a day. J Yes A About approximately for 1 hour. Now we may not do it in the surgery, we may go somewhere else to do that, umm and we will talk about what's happened during the day, what's happened in previous shifts that somebody might have missed so there was a constant feedback umm I don't get cross I get upset if my (mumbled) team can't don't feel they can talk to me, that they aren't telling me what's going on, we don't keep secrets umm you know. We all know what our patients are doing and where they are at (Page 10) If I want to gain support, no, because I also look on my team as my friends, umm I will also go and talk to other members within the practice and be it GP's, or the Health Visitor who is a very very good mentor to me, she umm she has got years and years of experience, I either has this or the District Nurse, so it is quite good I can go and talk to her and I dump my problems on her dinner plate so to speak and we talk through them I get through them that time (Page 10) No, I say no, depends where you are I think, I am very lucky I have got a very good team here, I think individual support for the professionals when they providing bereavement support has got to be very very strong because it can be incredibly draining you go home from it and be absolutely exhausted, and you think, I have only been there for two hours and talked, but mentally it can be a very very big drain umm so as long as the support networks are in place for the rest of the professionals doing that support for the families umm. (Page 13)		they very good (door closes) and they ask for clinical supervision at least twice a year, preferably three times a year or whenever we need it. I can ring up my clinical supervisor and say "help"	

Participants	Team	Family	Clinical supervision	Others
DN 14	the colleagues, you know all your colleagues I mean even the girls downstairs often these patients are known to them (Page 10)			You know, that they either get a lot of support from fellow colleagues at the surgery or they get none at all and they are left to flounder and obviously some of us feel it more with one particular patient than others, you know there are those that you can't help but becoming very fond of you know and you do feel a sense of a loss you know and its almost because you have often become like an extended member of the "family" (Page 10)
DN 15	I try to keep my distance because of that but there is obviously certain times when you do draw much closer to one person than another and so you have to umm probably discuss it with your colleagues as much as anything which I find that really useful we do that with all sorts let alone bereavement issues, we have got a big support network really here to actually only do clinical supervision as well (Page 7)			I mean there are certain GPs that you can discuss things with more than others and I work with one particular GP who is extremely sensitive to the families needs and we discuss long and hard about approaches to care and support of the family and umm and (mumbled) PR work mainly for is totally distant and funnily enough though his patients that he is lovely you know you always get the feedback but umm he is not the sort who can share all those issues with me for whatever reason but the others you can (Page 7)
DN 16	personally I work in a very good team and we meet three times a day and if any of us are on a bereavement visit which we find particularly difficult and that does happen quite often then we share it with each other we also do have clinical supervision so if you have any problems like that you know "I can't cope with this" then you can take it to your clinical supervisor (Page 7) But we have worked together for a long time all of us, we have been together for 12 years, the newest member of staff been there 12 years (Page 9)		You do have umm umm two set dates a year as it is now sort of compulsory for twice a year but if you had a specific problem and umm you could ring them and say I really need to discuss this with you (mumbled) pretty flexible, but it has never come to that because I mean within your team there is always someone who you can share this with you know (Page 7)	Pretty much so they are pretty good GPs here umm obviously some are better than others like the rest of us you know but a and they too have the same problems as they have done the first bereavement visit before you have gone in they well you know find the patient at their lowest ebb when they are crying and very upset and they find that very hard to deal with too because they very often come to us and say I (mumbled) this you know I felt terrible which is good cos they are coming to us and also they are showing a bit of emotion and feelings and I think it is important to show it. (Page 7)

Participants	Team	Family	Clinical supervision	Others
DN 17	We get support from one another really (Page 4) Oh peer support I think as I have said (mumbled) staff nurse that I work very closely with and as a team if we have been involved and there are four of us (banging) involved in looking after somebody we always talk about these things and we meet everyday so umm J Do you A We get support from one another really (Page 4)		And I do have it, so that would be something else if I needed to talk to someone about it. (Page 4)	
DN 18	Now a few years ago we had umm a lot of deaths in quite close together and it was before the hospice was opened so we were having a lot of people at home and we were very well I was ah I felt that I I didn't support my team because it wasn't until a while down the road when things were developing and I thought to myself I stood back and thought you know we are all suffering from bereavement umm and it didn't twig straight away because we were so busy and you know well that was my excuse so now we try umm we try and be there for one another and support one another we have two briefs every day so we discussed the issues umm and we share the work so that one person isn't going in all the time to take all all of the responsibility, you know ah and we would go together and things like that. (Page 7)		Do you have clinical supervision. A Yes J Is that helpful enough A Yes it is umm J Is that a regular event or is it when you need it A Umm the policy is it is three times a year, but available at any time, so umm my own supervisor I know I can ring up and say to her oh I am (mumbled) or I am finding things difficult at the moment and talk through issues with her yes (Page 7)	
DN 19	My support, well I have got a very supportive team here, we talk a lot, umm, (mumbled) about issues that any of us are concerned about and that will come up if an emotional one would come up if you know (Page 6)	If there was a tragedy of some sort, be it whatever, and I have also got a sister who is a district nurse J Right A Umm and another sister who is a Marie Curie nurse another sister who is in caring and my mother who was a nurse so I don't tend to go to my family very much J Umm A I tend, sorry my children I should say, and my partner, I tend to go to my sisters because they know exactly what I am dealing with (Page 6)		

Participants	Team	Family	Clinical supervision	Others
DN 20	J Ok. How do you get support if you need it. A Well you talk you talk to your colleagues J And that would be you're the best way that you get your support A Mmmm (Page 4)			
DN 21	No actually what we do is we work in a work in a smaller small team and we meet up quite often actually and we get (mumbled) quite a lot of support I mean we get on quite closely there is only me and a staff nurse and an auxilliary (Page 7)	I would go home and tell my husband (laugh) (Page 7)	clinical supervision deals more with what you feel is bothering you you know and if it doesn't umm like I said because the staff nurse and myself we work closely and we share the visits between us, so we support each other really, so you feel if there is a problem you can talk about it to each other on an informal (mumbled) I mean you could use clinical supervision if you felt you had a problem (Page 7)	
DN 22	We've got a fairly good team and it's that's the crucial thing I think there is five of us, four of us are part time and one of us is full time. Um, and we meet every lunch time and we talk about you know, all the patients and discuss if we feel there are some particular area or if we feel we are not the right person with somebody, which does quite often happen, you know some people you just click with better than others, um then we decide who best to go in and see that person through. So, it isn't really something I take, take home unless there has been something particularly traumatic, if it's been a young death, um then yes, you do take that home. Especially if there were young children involved. I think because you, I relate very much to that (Page 9)		We do get clinical supervision, yes yes we get it about six monthly or thereabouts (laughs) J Is that useful? a Um I have never used it for that purpose I have to be honest, I mean the clinical supervisor is smashing and I wouldn't have a problem discussing it with her but I have never had a bereavement issue that we haven't sorted out in house. Yes (Page 10)	

Appendix 18

Post interview letter and questionnaire

University Surgical Unit
F Level Centre Block, Mailpoint 816
Southampton General Hospital
Tremona Road
Southampton, SO16 6YD

Direct line: 02380 794397
Email: jb11@soton.ac.uk

Sunday, June 16, 2002

Re: District Nurse interview regarding bereavement support

Dear

On .... last year you were kind enough to participate in an interview for my research looking at bereavement support in the community. This research followed on from my survey of district nurses, which has now been published in the Journal of Advanced Nursing. ***Birtwistle, J., Payne, S.A., Smith, P., & Kendrick T. (2002) The role of the district nurse in bereavement care. Journal of Advanced Nursing 38(5), 467-478.*** If you would like a copy of that article in either paper version or emailed electronically as an Adobe pdf file please let me know and I will get it off to you as soon a possible.

Since I saw you I have changed jobs and now work at the University Surgical Unit as a Research Nurse / Co-ordinator on a large national study. I also work as a staff nurse on Ward F9 (surgery). In addition in my own time I continue to write up my bereavement research, which I now hope to complete before the end of the year. This will contribute towards my PhD.

I am currently analysing and writing up the district nurse interviews, which you helped with and would like to ask for your help once again. In total I interviewed 22 district nurses from a variety of areas and backgrounds. To be precise in my write up and analysis I wish to create an anonymous profile of the participants. Unfortunately, I did not get enough details at the time of the interview and in light of the findings of the survey some of these may be very important for my analysis. The results of the survey identified three key factors that influenced the practice of district nurses. These were the age of the district nurse, whether they had a degree or diploma and the area of employment

To help me in my analysis I would be most grateful if you would complete and return the enclosed brief questionnaire that would allow me to produce an anonymous profile of those interviewed. However, I must stress that when I write up the study it will be completely anonymous and you will not be identifiable from any details. The purpose of the profile is to show the diversity of the sample of district nurses and also to look for any links with the findings from my survey. The questionnaire will take less than a minute.

I have attached the brief questionnaire and stamp addressed envelope. If you have any queries or want to discuss this with me please write, phone or email me at the above contact and I will help in any way I can.

I appreciate your time and thank you in anticipation.

Yours sincerely

Jon Birtwistle

Re: District Nurse interview regarding bereavement support

Anonymous profile of district nurses

Please would you answer the following questions and return them in the stamp-addressed envelope.

1 What was you age at the time of the interview? (please tick one only)

20-30	31-40	41-50	51 (or older)

2 At the date of the interview how long had you been qualified as a nurse?

......................................years

3 At the date of the interview how long had you been working on the community as a district nurse?

......................................years

4 At the date of the interview how long had you been working in that post?

......................................years

5 At the date of the interview what was your nursing Grade? (please tick one only)

D	E	F	G	H	I

6 At the date of the interview did you have a degree OR diploma (any subject) (please tick one only)

Yes	No

7 Did the interview influence or change any of your practice?

(For example did it result in discussions with colleagues about bereavement support? Or result in the development of any local bereavement policies etc. Or did it make you want to attend a course on bereavement?)

Please give details here and on the back if appropriate.