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**EXPLORATION AND DEVELOPMENT
OF BEREAVEMENT CARE FOR OLDER
PEOPLE**

Audrey I. Stephen

A thesis submitted in partial fulfillment of the
requirements of Robert Gordon University for
the degree Doctor of Philosophy

May 2011

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ABSTRACT

AUDREY I. STEPHEN

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy awarded by Robert Gordon University

Exploration and development of bereavement care for older people

The rising population of older people in the UK (Office for National Statistics 2010) and pressure on healthcare services to reduce costs indicate the necessity of developing strategies that enable coping and independence. Loss through death of close family members, partners and friends is a key factor that inhibits physical, emotional and social well being of older people. The research carried out for this thesis explored bereavement in healthcare settings where contacts with bereaved older people commonly occur, and used data collected to develop guidelines for practice. The guidelines provide research informed enhancement to bereavement care and develop opportunities for meaningful interactions. They complement current policy development work on bereavement in healthcare settings (The Scottish Government 2011).

A qualitative design drawing on phenomenological methodology was used to explore healthcare staffs' experiences of caring for bereaved older people, and older people's experiences of being bereaved and bereavement care. Theoretical sampling took place to recruit staff from a range of roles in general practice and community nursing, hospital wards and care homes, as well as a small sample of bereaved older people. Thirty nine participants took part in in-depth interviews that yielded four key themes:

- bereavement care depends on a relationship between healthcare staff and relatives;
- preparation for a relative's death may not equate to preparedness for bereavement;
- the 'Open Door' to bereavement care is only slightly ajar, and
- bereavement care supports progression of the 'Rolling Ball' of life.

The themes informed development of the guidelines in terms of structure and content. Recommendation statements consider bereavement care before the

death; at the time of the death; and follow up in the weeks and months afterwards. Criteria in the recommendations provide suggestions for enhancements to practice that facilitate appropriate response to bereavement in older people. Consultation on the guidelines provided positive feedback that identified the potential to promote consistent interactions with bereaved older people, respond to needs and support coping.

OFFICE FOR NATIONAL STATISTICS, 2010. *National Population Projections*. London: Office for National Statistics. Available from: <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=8519> [Accessed 10th May 2011]

THE SCOTTISH GOVERNMENT, 2011. *Shaping Bereavement Care*. Available from: [http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/1006525/CEL%209%20\(2011\)%20Shaping%20Bereavement%20Care.pdf](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/1006525/CEL%209%20(2011)%20Shaping%20Bereavement%20Care.pdf) [Accessed 10th May 2011]

Keywords older people; bereavement care; health services; qualitative; guidelines; evidence based practice.

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KEY TERMS AND ABBREVIATIONS

AGREE	Appraisal of Guidelines for Research and Evaluation in Europe
CAQDAS	Computer Assisted Qualitative Data Analysis Software
Care home	Includes nursing and residential homes
Carer	Family care giver
CHAIN	Contact, Help And Information Networks
CHP	Community Health Partnership
CSO	Chief Scientist Office
DOH	Department of Health
GBRIG	Grampian Bereavement Resource and Interest Group
JBI	Joanna Briggs Institute
NES	NHS Education Scotland
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NHS QIS	NHS Quality Improvement Scotland
PTSD	Post Traumatic Stress Disorder
REC	Research Ethics Committee
R&D	Research and Development
SIGN	Scottish Intercollegiate Guidelines Network
SPPIRe	Scottish Practices and Professionals Involved in Research

CHAPTER 1

INTRODUCTION

Across the life span older people are most likely to experience loss through death of a family member or friend, and many may even suffer a succession of losses. However, support for older people in the time leading up to a loss, at the time of loss, and in the days, weeks and months afterwards is inconsistently provided within healthcare services (Stephen et al 2009). Bereavement care services are traditionally well developed in palliative care but there is little evidence of replication in non specialised healthcare settings where deaths are more likely to occur (Field et al 2007). In addition, previous research has identified a lack of clarity about care provided for the bereaved in general hospital wards, care homes and in community settings, and there is no particular provision for older people (Stephen et al 2009).

The study reported in this thesis explores bereavement care for older people as it is currently provided, from the perspective of both healthcare staff and bereaved older people. Data collected was used to inform the development of guidelines for bereavement care for older people for use in healthcare settings. This introductory chapter outlines the significance of the topic in the context of sociological perspectives of old age, current theory and research, and UK healthcare policy development work in terms of bereavement. It ends with an overview of the thesis, including the methodology and methods chosen to carry out the work.

1.1 Modern old age

In mid 2009 the population of the UK was 61.8 million people and 12.4 million were of retirement age. There has been a gradual rise in the proportion of people aged 65 years or more, from 15% in 1984 to 16% in 2009, and women outnumber men. This proportion is projected to rise to 23% by 2034, though the sex gap may narrow. However, the fastest increase will be in number of people aged 85 or more and 3.5 million is predicted by 2034. This will account for about 5% of the total population (Office for National Statistics 2010). There is a view that this represents a 'demographic time bomb' (The United Nations Programme on Ageing 2007) of burden and a continuing challenge to

maintain the rising population of older people. The increase in numbers has led to government and health and social care providers becoming concerned about costs of health care, pension provision, and the maintenance of older people's well being. A key priority is for people to remain independent for as long as possible (The Scottish Executive 2007). Consequently, the current focus of service delivery for older people is on such things as health promotion, encouraging self management of long term conditions, maintaining independent living and enhancement of equity and fairness of access to services (Department of Health [DOH] 2008).

Current cultural perspectives of ageing identify a process that has moved from being something that happens to people, to recognising that it is something that people become involved with, bringing to it their individual experiences and interests (Gilleard and Higgs 2000). Like younger counterparts, older people are a diverse range of individuals who experience stability and change, enter new roles and withdraw from others (Gubrium and Holstein 2000). Experiencing longer retirements has led to people maintaining a range of interests and activities that are driven by better health, better financial stability and increased liberalism than previous generations of older people. In general, it appears that boundaries between phases of the life course have become less differentiated (Biggs 2006).

Old age, however, continues to be bound up in ambiguous and negative stereotypical images that may be seen to affect the behaviour of older people. This may be the result of social policies and inevitable physical decline in old age (Gilleard and Higgs 2000, p90). However, Hazan (2000) indicated that the negativity may be misconceived and older people consciously counter these images through their relative freedom from social pressures, each having individual histories, involvements and social networks, and by exercising freedom of choice in making changes to their situations. This has, additionally, led to suppression of conscious thought about the reality of ageing and the certain knowledge of becoming older, and indeed much older than has been historically experienced (Biggs 2006). However, lapsing into deep old age may eventually exclude the older person from the roles they

have carved out for themselves and indicates an inevitable acceptance of infirmity and death (Gilleard and Higgs 2000).

This discussion appears to indicate that, though transition to old age is blurred, the phase of old age itself is now more subdivided than previously. However, this division is not universally experienced by older people and is dependent on much more than longevity alone (Blaikie 2006, Paul, Ayis and Ebrahim 2007). Common experiences of being an older person, regardless of any particular age differential, are challenges to health, living arrangements, family relationships, social integration and spirituality (The Scottish Executive 2007). In addition, a range of losses, including loss through death, are key factors (Bennett et al 2010).

Traditionally the role of supporting an older person to live independently fell to their family. However, changing patterns of family circumstances mean that there is now greater diversity in relationships, living arrangements and responsibilities that lead to concern about the future ability of families to care (Blackman 2001, p12). Increased numbers of people are living together but may be unmarried and there is more divorce and separation, remarriage and inheritance of step families (Harper 2006). In addition, the substantial involvement of women in the work force has reduced the availability of family care (Blackman 2001). However, for older people, complexity in family structure and living longer means that they may be more involved with supporting their extended families, while receiving mutual support. On the other hand, where there is lack of support and conflicting expectations between family members the negative effects of becoming older may become more apparent. In fact, reciprocal relationships depend on health and financial resources, family structures and networks (Harper 2006). Blackman (2001, p160) additionally indicates that older people generally wish to continue to live apart from their children, though most maintain a close bond. However, this does not guarantee social inclusion and loneliness may not be ameliorated by contacts with family members.

For many people living alone becomes a usual experience of modern old age and 2006 figures reported that 60% of women aged 75 or over lived on their

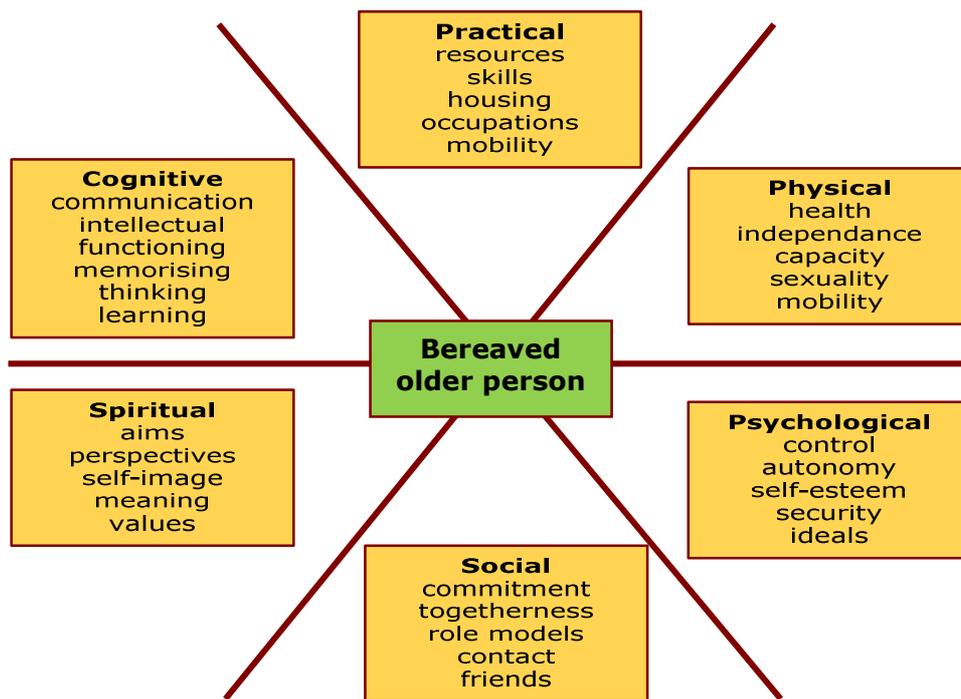
own (Office for National Statistics 2008). The proportions of men living alone are substantially less, however, longevity in men is predicted to rise and the mortality gap between the sexes to narrow (Davidson 2006). This means that a higher proportion of older men will be widowed. Marital status is closely related to perceived emotional and social support, and spousal loss may be the most important factor contributing to the experience of becoming single again as socially, psychologically and practically challenging (Luanaigh and Lawlor 2008). However, most people live in social and cultural networks from which they receive considerable support that allows them to function independently for most of the time (Davidson 2006).

In general, older people, particularly in late old age, will at some point come into contact with healthcare services and a range of healthcare practitioners. Providing fundamental care for older people in a skilled and caring way would appear to be a key component of the role of nursing and medical practitioners. However, the Nursing and Midwifery Council (2009) has recently published guidance on caring for older people that supports the suggestion that high quality person centred care may not be universally available (Woolhead et al 2004). The guidance suggests a move from medically orientated care to a philosophy of relational care and working collaboratively with older people to promote health and prevent ill health (Nursing and Midwifery Council 2009). The vital role of partners, families, carers and friends has also been identified and their role in decision making acknowledged. This provides a basis from which bereavement care for surviving older people who may have lost spouses, partners, other family members and friends may take place.

1.2 Modern old age and loss

Bereavement in later life can put stress on an older person's capacity to cope and be self caring, as well as on their health (Hansson and Stroebe 2007). A complex picture of bereavement for an older person emerges when loss of a close relative or friend is experienced in addition to a range of other losses associated with advanced age. The broad range of potential losses is illustrated in The Wheel of Loss (Adriaensen 2006) (Figure 1 below). As illustrated, losses for the older person may include combinations of practical, physical, psychological, social, spiritual and cognitive factors. Each bereaved

Figure 1. The Wheel of Loss (Adriaensen 2006)



older person will have a unique set of factors and circumstances that mean their experience of amalgamating bereavement into their ongoing lives is highly unique and individual. Reviewing the evidence on bereavement and mental health in older people, Parkes (1997) noted that the impact of a series of losses, including bereavement, on physical and mental health may not be as devastating as expected. However, he further identified that there may be a substantial minority for whom accumulated losses lead to psychiatric ill health (Parkes 1997). More recent research suggests that achieving balance between losses and gains can be beneficial (Bennett et al 2010). However, it is difficult to see how a loss through bereavement may be balanced, for example, by gaining household maintenance skills. That is not to say that some aspects of the 'Wheel of Loss' may not be experienced more positively after bereavement, for example, there may be a regaining of control for a widow who has cared for her husband for a period of time in the lead up to his death.

Research that explores factors related to bereavement in all adult groups, including older people, indicates that people who are bereaved are more likely to have excess mortality rates in the first six months after the loss from many causes, including suicide (Stroebe, Schut and Stroebe 2007; Buckley et al

2010). Mortality in bereaved spouses has been attributed to psychological distress and difficulties like loneliness, social changes, changed eating habits, and loss of economic support (Stroebe, Schut and Stroebe 2007). In addition, coronary heart disease may account for a substantial proportion of increased deaths of bereaved spouses. This is attributable to biological changes as well as psychological distress and behavioural changes (Buckley et al 2010). Other difficulties related to physical health that may occur following bereavement, include higher rates of disability, medication use, and hospitalisation (Stroebe, Schut and Stroebe 2007).

In older people, Hansson and Stroebe (2007) have identified that bereavement experiences in terms of physical and mental health consequences, behavioural and social affects are similar to that of younger counterparts. The bereavement trajectory also appears to be generally similar, with intense grieving in the first few months and gradual adaptation taking place thereafter. However, individual reactions to grief may be diverse, with some older people being extremely distressed while others display constraint. A study by Lee and Carr (2007) identified contextual factors related to the loss that may have long term affects on physical functioning in older people. Particularly useful predictors were serious health problems before the spouse's death, and not being with the spouse at the time of the death. However, predictive risk factors for adverse reaction are less sensitive in older people, as proportions of variability may be due to age related changes (Hansson and Stroebe 2007). Additionally, Hansson and Stroebe (2007) have warned that research does not take account of later life developmental theories. However, the overall impression given by this type of evidence remains that, since bereavement poses health risks, healthcare providers should be involved in risk assessment, health promoting activities, and supporting people to cope.

Bereavement researchers have additionally identified common patterns of grief, including resilience, in older people who have lost a spouse. The trajectories indicate particular aspects of the bereaved person's health profile prior to the death, circumstances surrounding the death, and reaction to the

death that may affect bereavement. Three common patterns of bereavement outcome for older people have been identified:

- short term disruptions in functioning, for example, increased depression, cognitive problems, health problems;
- chronic disruptions in functioning;
- relative absence of grief reaction (Bonanno et al 2002).

An understanding of these patterns is useful as an aid to identification of those who may need support in addition to that provided by family and friends, and those to whom additional support would be less beneficial (Bonanno, Nesse and Wortman 2004). Table 1 (overleaf) gives the factors found to contribute to each reaction type and suggestions for whether or not intervention is needed and what should be addressed through intervention. The table provides some indication of need based on a broad differentiation of reactions to the death. It also identifies, in common with other research, that most older people amalgamate the loss into their lives and do not suffer long term disruptions in functioning (Stroebe, Schut and Stroebe 2007, Metzger and Gray 2008).

1.3 Theoretical perspectives on bereavement

Examination of bereavement theories additionally facilitates understanding of bereavement responses, and of coping and adaptation to loss. Perspectives are relevant to adults in general and older people, the group of interest for this thesis, are assumed to be included. Traditionally theorists described grief as a progression through identifiable phases or stages to a point of recovery. Stages were described by prominent bereavement researchers like, Bowlby (1980), Parkes (1996) and Kubler-Ross (1995). Bowlby's (1969) attachment theories that identified behaviours characteristic of different attachment types were instrumental in the development of stages of loss reactions. However, stages were not described as rigidly occurring and some blurring and movement between stages was identified, as discussed in Parkes (1997). Developing stage models, Worden (2001) described tasks of grieving that specifically identified what the bereaved person needed to achieve to make progression through the bereavement journey:

- accepting the reality of the loss;
- working through the pain of grief;

Table 1. Reaction type, contributing factors and intervention

Based on research with older people carried out by Bonanno, Nesse and Wortman (2004)

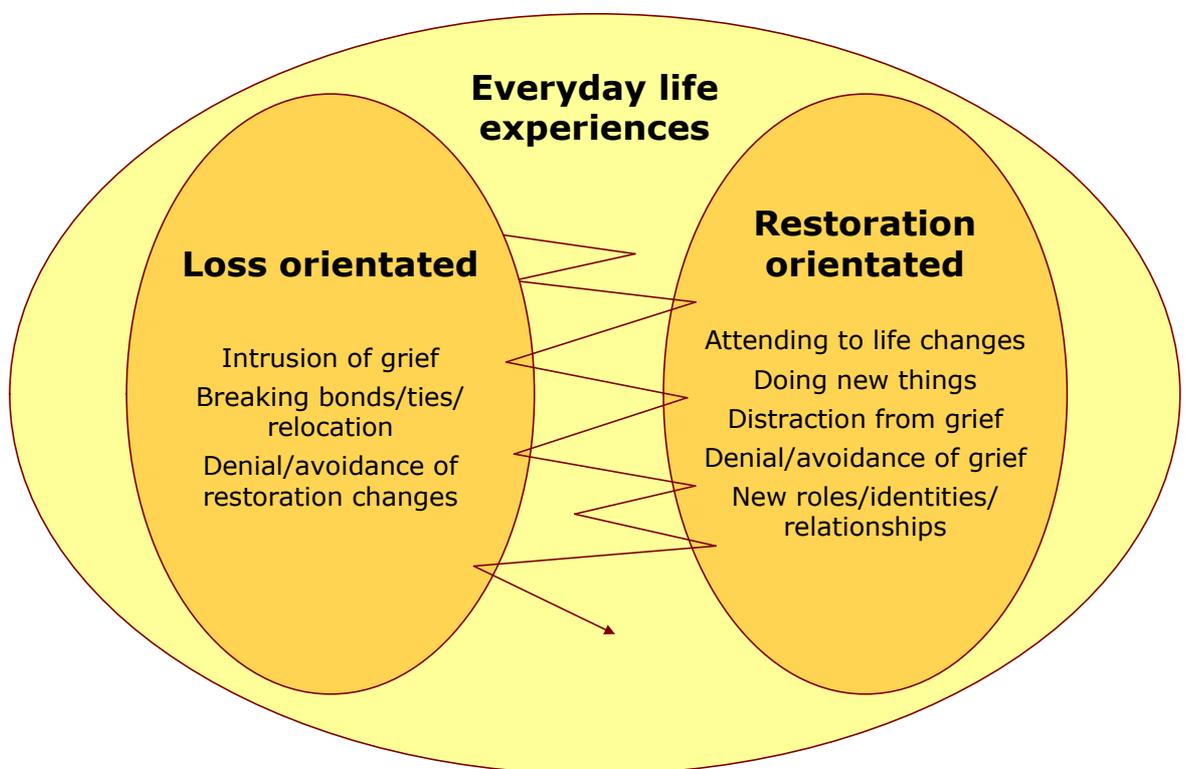
Reaction	Contributing factors	Intervention
Little evidence of intense grieving	Satisfying marriage Less time thinking about loss, searching for meaning or using avoidance strategies Finds comfort in memories	Unlikely to need or benefit
Depressed before death - improved after death	Spouse's death likely to mark end of long term cause of stress Marriage less likely to be satisfying Spouse likely to have had poor health Unlikely to be in denial Positive memories of life with spouse	Likely to cope well and not need intervention
Chronic grief	Emotional and cognitive disruption at time of the death Likely to have yearning feelings and emotional turmoil in early stages Think and talk about the death more often Search for meaning in the loss up to 18 months into bereavement	Help to process the loss and make meaning
Chronic depression	Emotional difficulties prior to the loss worsened by the loss Not influenced by time since loss	Help to build self esteem; deal with daily stresses

- adjusting to the environment without the deceased;
- emotionally relocating the deceased.

In addition, mediating factors were identified that influence the achievement of grieving tasks, for example, the nature of the attachment and the mode of the death. Theorists also recognised great variability between people in rate of progress of adaptation and saw *grief work*, the process of confronting the loss and accommodating it in ongoing life, as key to progression and reaching a state of amelioration (Parkes 1996).

In more recent years models of grief have become more sophisticated and incorporate a range of emotional, practical and social challenges faced by the bereaved. They explain grief as a transaction between how an individual understands their world and what is happening in their life (Payne, Seymour and Ingleton 2008). This idea is reflected in the Dual Process Model of Stroebe and Schut (1999) that proposes movement between loss and restoration focused coping styles (Figure 2).

Figure 2. The Dual Process Model (Stroebe and Schut 1999)



Loss oriented grieving involves concentration on dealing with aspects of the loss with respect to the dead person and, in general, is the major focus for the bereaved in the early days and weeks of bereavement. Restoration orientated grief involves adjusting emotionally and practically to changes that are secondary consequences of bereavement, for example, mastering the tasks that the deceased had undertaken (finances, cooking, household maintenance). These may be tasks that are generally more difficult for older people. A further concern, integral to restoration, is the development of a new identity, for example, from spouse to widow. In addition, a process of

oscillation, where the bereaved person at times confronts and at other times avoids the tasks of grieving is key to coping and adaptation. The model describes a flexible waxing and waning over time with early domination of loss orientation, and later on more restoration orientation and a gradual reduction in bereavement related stress.

A third model of grief to consider is much more rooted in sociological perspectives and changed social environments in which people operate. This is the theory that recognises continuing bonds with the deceased person (Klass, Silverman and Nickman 1996). Historically working with bereaved individuals, psychiatrists and psychologists aimed for the breaking of bonds to allow moving forward to a point when the loss is no longer a focus. However, recent research has identified that *grief work*, requires the bereaved to adjust without necessarily relinquishing the bond. In older people it has been identified that successful grief journeys do not depend on disengaging from the deceased, or breaking bonds (Costello and Kendrick 2000). Reconstructing a meaningful life can include building a new relationship with the deceased based on accepting the ongoing bond (Field 2008). Continuation of bonds allows development of a narrative of the deceased and gives meaning to life before and after their death (Klass, Silverman and Nickman 1996, Walter 1996). Continuing bonds that acknowledge the loss are seen as part of the spectrum of normal grief reactions, while those that do not are seen by some theorists to impede *grief work* (Field 2008).

A further key issue in bereavement research and theorising is in understanding determinants of grief and enabling identification of those who are at high risk of getting into difficulties. Extensive research has gone into developing risk assessment criteria for predicting risk of a bereaved person having a complicated grieving trajectory. Being clear about who is at risk means that help can be focused where it is most needed (Parkes and Prigerson 2010). Principle determinants of poor outcome, not necessarily in isolation are:

- the relationship with the deceased and whether it is dependent, avoidant, or conflicted (Parkes 2006);
- the gender of the bereaved;

- age of the bereaved and deceased;
- the mode of the death, particularly trauma;
- personal vulnerability (closely related to the relationship with the deceased);
- lack of social and family support (Parkes and Prigerson 2010).

However, Parkes and Prigerson (2010) in their latest work indicate that the determinants may in actual fact be the underlying causes of grieving difficulties. The difficulties themselves may be the risk factors of poor outcome, for example, adaptation problems, and severe and lasting distress. In addition, there is no clear evidence that bereavement services are of benefit and may only bring forward improvements that would happen anyway (Parkes and Prigerson 2010). Risk assessment is a complex process and should not lead to universal offering of services to those with one or two criteria, but should be directed at those at most risk of adverse outcome. Identification of bereaved people who may need additional services is, therefore, complex and may require a degree of personal judgement on the part of the assessor as well as being dependent of the timing of the assessment.

1.4 Healthcare services and bereavement

The factors outlined above indicate that targeting bereavement care services to those with most need, who may not be older people, is complex in practice. Decisions are currently based on either clinical judgement of need, or risk assessment tools that may lack reliability and have limited scope (Relf 2008). However, bereavement care that supports people through the grief journeys as depicted by the theorists is a well established aspect of service delivery in hospice and palliative care settings across the UK (Stephen et al 2009). The philosophy of palliative care strongly advocates responsibility for care staff to support patients and their families throughout an illness, to the terminal stage and into bereavement (The Scottish Government 2008a). 70% of hospice deaths in Scotland from 2004-2008 were of older people (ISD Scotland 2010), therefore, a proportion of those supported in bereavement were also likely to be older spouses. Guidance on development and delivery of bereavement care is provided within palliative care guidelines by, for example, the National Institute for Health and Clinical Excellence (NICE) which recommends a three component model:

- provision of information that assists people to understand the grieving process whilst recognising grief as a normal process that people can and will adapt to with family and friends' support;
- more structured review of experiences and provision of opportunities for reflection for some who may require additional support;
- appropriate referral to a higher level of support, for example, from psychiatric or psychological services where necessary (NICE 2004).

The NICE guidelines do not differentiate between the needs of older bereaved adults and those categorised as young. It is unclear how universally applicable the guidance can be, and what specific recommendations there may be for bereavement care for older people. However, a high level of expertise has developed in many hospices with many employing trained professionals who have bereavement support as part of their role. A survey of UK hospices identified provision of a range of services, which may be helpful to older people, including one to one support sessions, group counselling, follow up visiting, written information for the bereaved, and memorial services (Field et al 2007). The replication of bereavement care skills in other more generic healthcare services is, however, limited. Consultation may regularly take place on a range of issues, for example, symptom management for patients in general hospitals and in the community, but there is no similar sharing of experience on bereavement care (Field et al 2007, Payne, Seymour and Ingleton 2008).

Nevertheless, significant engagement with bereavement and bereavement care has been found in a range of health and social care services (Wimpenny et al 2006, Stephen et al 2006). In particular, pockets of work take place in accident and emergency departments (Williams et al 2000), intensive care units (Tunncliffe and Briggs 1997), maternity services (Appleton, Gibson and Hey 1993), and children's services (Macpherson and Emeleus 2007) within the National Health Service (NHS). However, in medical, surgical and elderly care wards, community hospitals, general practice, community nursing and in care homes there is less clarity about what is done as regards follow up support for bereaved older people (Stephen et al 2006). In particular, little information exists about communication between services, for example, hospital wards and general practice about bereaved older people. This is incongruent with

the fact that the care of older people commonly occurs in these areas and deaths are more likely to take place. Of the approximately 75,000 deaths from cancer in Scotland in the years 2004-2008 about half occurred in NHS acute hospitals (77% of whom were older people, ≥ 65 years), and a quarter in the patient's home (71% of whom were older people), with only about 18% taking place in hospices (ISD Scotland 2010)¹. In addition, it is known that 9,281 deaths occurred in care homes during 2008 (The Scottish Government 2008b), and a large number will be of people aged 65 years or more who will leave older bereaved relatives.

Continuity of care provision is the desired experience of the bereaved where those who provided support during the end stages of the dying relative's life continue to support in bereavement (Kissane 2008). However, pressure on staff in acute hospitals can lead to neglect of bereaved relatives. Staff often have fleeting contacts with families and little opportunity to develop a relationship that may facilitate bereavement care and follow up (Kissane 2008).

1.5 Bereavement care development in the context of current Scottish health and social care policy

The current research project takes place within the context of increased interest in bereavement and bereavement care in recent years from government level within and across all the countries in the UK. Concerns and difficulties for the bereaved came to the attention of policy makers in the wake of enquiries into paediatric cardiac surgery at Bristol Royal Infirmary (Kennedy 2001), and organ retention at Alder Hey Children's Hospital in Liverpool (Redfern, Keeling and Powell 2001). This resulted in policy development that led to rolling out of bereavement co-ordinator posts in health authorities across England and Wales and the provision of information and support for bereaved families (DOH 2005). Development work in Scotland by the devolved government was delayed, though there was continued interest in government departments, for example, NHS Quality Improvement Scotland (NHS QIS) and NHS Education Scotland (NES). A programme of research

¹ Similar data for other disease states is unavailable.

work that included a literature review on bereavement across the lifespan (Wimpenny et al 2006) and consultation and mapping of services for the bereaved (Stephen et al 2006) was commissioned and has led to current national policy development work. *Shaping Bereavement Care*, the framework for action for bereavement care in NHS Scotland provides guidance to health boards on the introduction of certain requirements for the development, planning and implementation of bereavement care services (The Scottish Government 2011). Launch events took place at health boards across the country during October 2010 to introduce the guidance, and following consultation the finalised document was published in February 2011. The focus of the guidance is on acute sector services, however, there is no section specifically about care for bereaved older people.

Other policy development in Scotland relevant to bereavement care services are *Living and Dying Well: A national action plan for palliative and end of life care in Scotland* (The Scottish Government 2008a) and *Spiritual Care Matters: An introductory resource for all NHS Scotland staff* (NES 2009). A key component within *Living and Dying Well* that has additionally been explored within a short life working group was raising awareness in healthcare organisations and in members of the public of issues relevant to death, dying and bereavement. The group's aim was to promote discussion of the topics and enable right choices to be made about end of life issues. There is some recognition that older people may have specific support needs and the need has been identified in some areas for building capacity in healthcare staff to support older people appropriately. The involvement of healthcare staff is key to enabling people to talk openly and incorporating time for staff to reflect on their experience may be a way ahead.

Spiritual Care Matters is a learning resource for all healthcare staff in Scotland that indicates areas of knowledge, practice and awareness that would benefit patient care. Again, however, the focus is general and there is no specific reference or section on spiritual needs of older people. It promotes spiritual care as both beneficial to the patient and the carer, and identifies support possibilities within the healthcare environment. The relevance of spiritual care takes on inevitable significance when healthcare staff interact with relatives

and friends of patients at the end of their life. Being supportive may involve listening to the patient as they express anxiety about the family they leave behind, the bereaved relative as they consider the meaning of their loss, or at a later stage as they amalgamate the loss into their ongoing life (NES 2009). In addition, by exploring issues such as meaning, purpose, relationships, and connectedness in their work healthcare professionals can be rewarded spiritually and be more able to cope with daily stressors (Wright 2005). These ideas are reflected throughout the current project in the thoughts of healthcare staff and bereaved older people as bereavement care provision is explored in depth. They are also followed up and included in the guidelines for bereavement care.

1.6 Bereavement care for older people in healthcare services

The overview provided above of bereavement and bereavement care described in the literature and theoretical perspectives, and developed in healthcare policy and practice has identified the importance of the topic. However, it has been generic in nature other than pockets of development in services for bereaved children and parents, or in palliative and cancer services. Considering that spousal loss in later life is the most common form of bereavement there has been little attention to risk factors, coping strategies and the influence of the context of daily lives of older people (Carr 2008). The Changing Lives of Older Couples study has empirically investigated grief in older people and found great differences in grief reactions and factors that exacerbate grief or promote resilience (Carr 2008). Factors like previous experiences of deaths, the expected death of the spouse, or the death less likely to be sudden may mean that older adults adjust to loss of the spouse more readily than younger adults. However, other stressors of ageing may affect coping resources and exacerbate loss reactions, for example, poor physical or mental health (Adriaensen 2006). Hansson and Stroebe (2007) identified four key themes in the bereavement experiences of older people that may be used to inform the development of capacity in healthcare services to provide support:

- highly diverse reactions to deaths, influenced by life experiences and increased adaptive potential;

- general resilience with growing sense of achievement and self discovery, though still likely to be emotionally and physically difficult;
- the criticality of the context of the bereavement, and the likelihood of it differing from younger people when disorganisation, loss of social roles, loss of income, loss of status and disenfranchised grief² are key considerations;
- outcomes of bereavement differ from those of younger people, and may include loneliness, social isolation, poorer health behaviours, housing difficulties and dependency.

In many healthcare settings bereavement and care of the bereaved is given a high level of priority. However, in general healthcare services, also introduced above, engagement of staff with bereaved relatives appears to be inconsistent and variable both between and within services. There is an overall lack of clarity about support for the relatives of a patient who is at the end stages of life, at the time of the death, or in the weeks and months afterwards. There are also no specific services or guidance on bereavement care for older people and the research base from which to draw may be lacking. No specific pathways could be identified in previous research through which older people receive or can access support. This study was developed to explore bereavement experiences of older people and bereavement care provided in the service areas of interest. The results of this exploration were used to develop guidelines that would be suitable for use in practice as a tool to inform the enhancement of services and to facilitate learning and discussion. For bereaved older people the guidelines may promote consistent care that supports people to be independent. Developing research that is grounded in healthcare practice and has outputs that are relevant to service users and staff is a key driver for the project.

1.7 Overview of the thesis

The thesis begins with a systematic review of the literature (Chapter 2) on bereavement and older people, and interventions developed to address

² Disenfranchised grief - term used to define reaction to a loss that is unrecognised by others, for example, of an ex spouse.

bereavement support and care needs. The qualitative research design used to carry out the exploratory aspect of the research study, identified as Phase 1, is then described fully in Chapter 3. Semi structured interviews drawing on interpretive phenomenological techniques were used to explore experiences of caring for bereaved older people, or for older people, of bereavement and their interactions with healthcare staff. Sampling and participant recruitment (Chapters 3 and 4) took place in the three healthcare settings of interest: general practice and community nursing; hospital wards; and care homes. Data was analysed using the framework approach of Spencer, Ritchie and O'Connor (2007) and the phenomenological interpretation methods described by Giorgi (1985). The emergent themes, provided in detail in Chapter 5, enabled the study to move on to a second phase of developing the guidelines and consultation. Themes were used to develop the practice guidelines (Chapter 6) for healthcare staff to inform the care delivered to bereaved older people they have contact with in the course of their work. The draft guidelines were distributed to participants in the study and others with an interest in the topic area. Feedback was collected on the usefulness of the proposed guidelines (also described in Chapter 6); whether it meets the needs of healthcare staff and bereaved older people; how it could be used in practice; anticipated benefits for staff and bereaved older people; and to gauge willingness to use the guidelines in practice. The consultation process informed the finalisation of a version for use in practice. Development of the guidelines for practice was the main aim of the study and clearly was the output of the research carried out. It was designed to assist healthcare staff to make decisions about care they provide to bereaved older people and encourage the development of opportunities to provide support. The research procedures, results, and outputs are discussed and critically analysed in Chapter 7 of the thesis, and Chapter 8 provides concluding comments.

The study was funded for a period of three years (one researcher working full time, the author of this thesis). Funding was provided by the Chief Scientist Office (CSO) of the Scottish Government Health Directorates. Ethical approval for the study was received from the local Research Ethics Committee (REC). A detailed timetable was drawn up for the work and, in general, it proceeded within the proposed time frame. However, the major difficulty experienced

during the project was in the sampling and recruitment of participants. This was time consuming and protracted and a lower number of participants was achieved than initially proposed. This was particularly the case for recruiting a sample of bereaved older people where options for exploring different recruitment strategies were limited. Re-engagement of participants for the consultation on the guidelines was also challenging with reduced numbers providing feedback. However, other contacts with an interest in bereavement and bereavement care as well as healthcare services were approached to provide feedback and validation of the guidelines. Full information about the research carried out is provided in the thesis and assessment is made of the rigour of the methods employed. The thesis continues with the literature review that amalgamates the results of previous studies in the area to build up the picture of what bereavement may be like for an older person, and what may be provided in terms of bereavement care in healthcare settings.

CHAPTER 2

REVIEW OF THE LITERATURE

Evidence from published qualitative and quantitative studies were systematically reviewed and used to develop an overview of research on bereavement and older people, and bereavement and bereavement care in healthcare settings. Relevant studies were gathered and objectively appraised and, where appropriate, results were amalgamated thematically. The aim of the review was initially to identify the meaning of bereavement for the older person. This would inform the development of enhancements to bereavement care at a later stage in the current study that were relevant to the experiences of older people. The review also aimed to assess the available evidence for supporting delivery of bereavement care to older people in the general healthcare services. In addition, reviewing the research assisted in the placement of the project within the body of available evidence and the identification of what it would add to knowledge in the area. The objectives set to guide the review and presented in this chapter were:

- search for primary research published from 1990 onwards in Western societies;
- extract data from included studies;
- assess the quality of studies;
- explore the meaning of bereavement for older people;
- identify the context of providing bereavement care;
- synthesis of the results of intervention studies to give overall assessment of effectiveness;
- review research on the management of grief in older people in healthcare settings.

The methods used for the systematic literature review are provided in detail in Appendix 1.

The findings of the review are presented below under thematic headings. Data extraction and quality assessment forms were completed for each study included in the review (see examples in Appendices 1A and 1B). Publication information, the databases in which the references were located, and the

overall quality status allocated to each study reviewed are tabulated in relevant sections below.

2.1 Older peoples' experiences of bereavement

The reviewing process outlined above led to the identification of four main themes relevant to older peoples' experiences of bereavement:

- physical effects;
- psychosocial effects (including loneliness);
- changed relationships with self and others;
- maintaining continued bonds with the deceased.

The findings are presented in the sections below and information about the studies included is contained in Tables 2 and 3. Studies were published in medical, nursing and social work journals from 1990 – 2009. One report considered to be grey literature was included. Most included studies were set in the UK or the USA. Others were set in Western Europe and Canada, with one reporting collecting data electronically from participants in the USA, Australia and Canada.

As background information to the current review it is worth noting that physical and mental health effects of bereavement have previously been identified in a review of research by Stroebe, Schut and Stroebe (2007). Across a wide age range bereavement was associated with mortality in the early weeks and months. In particular, the risk of mortality was found to increase post bereavement in young widow(er)s. It was further identified that recent bereavement increases the risk of physical morbidity and is associated with a wide range of psychological reactions to bereavement. In the current review, specifically focusing on bereavement and older people, two sub-themes were identified: physical health effects; and psychosocial effects.

2.1.1 Physical effects

High morbidity and mortality rates for all causes following loss of a spouse have been identified, particularly in the newly bereaved. Those with more symptoms before bereavement have highest mortality (Stroebe, Schut and Stroebe 2007). However, trends suggest that older widowed people are at less risk of death than younger widow(er)s, and mortality patterns may be

Table 2. Included studies – experiences – quantitative research

Author	Year	Publication	Title	Database	Quality
Van Baarsen, B., Smit, J.H., Snijders, T.A.B., & Knipscheer, K.P.M.	1999	Ageing and Society 19: 441-469	Do personal conditions and circumstances surrounding partner loss explain loneliness in newly bereaved older adults?	AgeInfo, ASSIA	Fair
O'Rourke, N.	2004	Ageing International 29 (3): 267-280	Psychological resilience and the well-being of widowed women	AgeInfo	Fair
Siegel, J.M. & Kuykendall, D.H.	1990	Journal of Consulting and Clinical Psychology 58 (5): 519-524	Loss, widowhood, and psychological distress among the elderly	Medline, Cinahl, ASSIA	Good
Hagedoorn, M., Van Yperen, N.W., Coyne, J.C., (et al)	2006	Psychology and Aging 21(3): 611-620	Does marriage protect older people from distress? The role of equity and recency of bereavement.	Medline, Embase, ASSIA	Good
Schulz, R., Beach,S.R., Lind,B. (et al)	2001	JAMA 285 (24): 3123-3129	Involvement in caregiving and adjustment to death of a spouse: findings from the caregiver health effects study	Medline	Good
Ott, C.H., Lueger,R.J., Kelber,S.T. & Prigerson,H.G.	2007	Journal of Nervous and Mental Disease 195 (4): 332-341	Spousal bereavement in older adults: Common, resilient, and chronic grief with defining characteristics	Embase	Good
Elklit, A. & O'Connor, M.	2005	Scandinavian Journal of Psychology 46: 439-445	Post-traumatic stress disorder in a Danish population of elderly bereaved	Medline	Fair
Burton, A.M., Haley, W.E. & Small, B.J.	2006	Aging and Mental Health 10 (3): 319-326	Bereavement after caregiving or unexpected death: Effects on elderly spouses	Medline, Embase	Good
Torges, C.M., Stewart, A.J. & Nolen-Hoeksema, S.	2008	Psychology and Ageing 23 (1): 169-180	Regret resolution, aging and adaptation to loss	Medline, Cinahl, Embase	Fair
Bowling, A.	2009	Age and Ageing 38: 527-530	Predictors of mortality among a national sample of widowed people: analysis of 28-year mortality rates	Medline, Cinahl	Fair
Grimby, A., Johansson, A.K., Sundh, V. & Grimby, G.	2008	American Journal of Hospice and Palliative Medicine 25(2): 81-87	Walking habits in elderly widows	Cinahl	Good

Table 3. Included studies – experiences – qualitative research

Author	Year	Publication	Title	Database	Quality
Bennett, K.M.	2004	Journal of Health Psychology (9) 3: 342-353	Why did he die? The attributions of cause of death among women widowed in later life.	Medline, ASSIA	Fair
Costello, J. & Kendrick, K.	2000	Journal of Advanced Nursing 32(6); 1374-1382	Grief and older people: the making or breaking of emotional bonds following partner loss in later life.	Medline, AgeInfo, ASSIA	Fair
Anderson, K. & Dimond, M.F.	1995	Journal of Advanced Nursing 22(2): 308-315	The experience of bereavement in older adults.	Medline, Cinahl, ASSIA	Fair
Hegge, M. & Fischer, C.	2000	Journal of Gerontological Nursing 26(2): 35-43	Grief responses of senior and elderly widows: practice implications	Medline, Cinahl	Good
Hockey, J., Penhale, B. & Sibley, D.	2001	Ageing and Society 21: 739-757	Landscapes of loss: spaces of memory, times of bereavement	AgeInfo, ASSIA	Good
Costello, J.	1999a	Illness, Crisis and Loss 7(3): 218-232	"Filling the Void": grief and loneliness in older adults.	ASSIA	Fair
Costello, J	1999b	International Journal of Palliative Nursing 5(5): 223-231	Anticipatory grief: coping with the impending death of a partner	Cinahl	Good
Bennett, K.M.	2005	Mortality 10 (2): 144-154	'Was life worth living?' Older widowers and their explicit discourses of the decision to live	Cinahl, ASSIA	Good
Bennett, K.M. & Vidal-Hall, S.	2000	Ageing and Society 20 (4): 413-428	Narratives of death: a qualitative study of widowhood in later life	AgeInfo	Good
Grief, C.J. & Myran D.D.	2006	Journal of Geriatric Psychiatry and Neurology 19(4): 209-215	Bereavement in cognitively impaired older adults: case series and clinical considerations	Medline, Embase	Poor
Pilkington, F.B.	2005	Nursing Science Quarterly 18 (3): 233-242	Grieving a loss: the lived experience for elders residing in an institution	Medline, Cinahl, ASSIA	Fair

related to ageing (Hansson and Stroebe 2007). Additionally, increased risk of sleep disruption, and increased tobacco and alcohol use have been identified in the early months following bereavement in all adults and early mortality may be a consequence (Prigerson and Jacobs 2001). However, only two studies that explore morbidity and mortality in older people specifically have been found, and these are reported below. This may indicate that older people are a group who may be viewed as requiring less in terms of bereavement support. However, the psychosocial and emotional effects that may result from bereavement (explored in section 2.1.2) indicate a variety of experiences and needs. For a minority of bereaved older people, physical health difficulties will occur and as such demand the attention of healthcare professionals.

Bowling (2009) studied the importance of predictors of mortality in widowed older people over a 28 year time span. However, the methods described were incomplete potentially limiting wider inference of the results. Face to face interviews with 361 elderly widow(ers) and 19 proxy carers were carried out at baseline. After 28 years further data collection took place with 27 survivors. Cox proportional hazards models of mortality were conducted. The study found that duration of survival was not significantly associated with socio-economic status, social network, support or participation, mental health, or coming to terms with the death. Variables achieving significance were age, sex, level of physical functioning, and interviewer assessed relief expressed at the death of the spouse. Cox models showed significant effect of male sex and older age on risk of mortality. Decreased risk was found in those who were physically active, and those who did not express relief after the spouse's death. In addition, excess risk factors for mortality after bereavement that were apparent up to six months were found to reduce over the longer follow up period.

Bereavement in older widows is also characterised by reduced physical activity. Grimby et al (2008) studied three groups of older women:

- Group 1. 39 consecutively selected widows of mean age 76 years whose partner had died in palliative care. Their physical activity was monitored at 3 months, 12 months, and between 4-5 years post

bereavement. They were also interviewed about their health and lifestyle.

- Group 2. 404 widows aged ≥ 65 , and bereaved 4 years or more. They were part of a large scale questionnaire study in which health and lifestyle questions were asked.
- Group 3. Participants in a population study of 76 year old men and women, 149 were widows and 109 married women. Some may have taken part in group activity programmes aimed at improving physical fitness. They were interviewed about their health and lifestyle.

Statistical analyses compared the groups. Results of this well designed study showed that widows spent less time walking in the first year of widowhood than married women. However, the amount they walked increased in the 5 years post bereavement. Not feeling well, particular musculoskeletal and cardiac problems, having less than two friends and not being in formal clubs were significantly associated with less walking. Reduced physical health and social isolation in the short term have been seen as barriers to widowed women taking part in physical activity. In the long term, lower levels of activity led to worsening health and inability to exercise. Most, however, will regain a certain level of activity as time since bereavement lengthens and social involvement increases. Possible intervention strategies are provision of information on health problems, and facilitating increases in social activity (Grimby et al 2008).

2.1.2 Psychosocial effects (including loneliness)

Siegel and Kuykendall (1990) studied depression in older men and women to determine whether there was a relationship with recent loss. The study used well developed and validated measures of life events and depression, and detailed statistical analysis techniques. A particular aim of the study, relevant to the wider context of bereavement in older people, was to assess the effect of non spousal loss on mental health. Findings were that poor health, unemployment, and loss of a close family member in the previous six months were related to higher depression levels. Widows were found to be particularly depressed along with those who were not church members. Non spousal loss was associated with depression in men but not women, and widowed men were more depressed than married ones. A further cohort study

by Schulz et al (2001) followed up carers aged 65 years or more over time to investigate the effect on them of the death of the person they cared for, and in particular looked at the effects of spousal death on depression symptoms, antidepressant use, health risk behaviours and weight as a function of level of involvement in caregiving prior to the death. This study was robustly designed and produced useful empirical evidence for the impact of carers' experiences on bereavement outcomes. Significantly higher levels of depression were found in bereaved carers who had felt strained while caring ($p < 0.002$), and levels remained high post bereavement. Depression levels increased significantly from pre-bereavement to post-bereavement in the non caring and unstrained carer groups. A slight increase in antidepressant use was found in non-carers after bereavement, but not for carers ($p = 0.05$). However, low numbers were included in this analysis limiting generalisability. Caring status affected health risk behaviours in the sample studied with the strained carers more likely to put their health at risk, however, a significant decrease in health risk behaviours in this group took place following bereavement ($p < 0.001$). Significant weight loss following bereavement was also found in the non caring group ($p = 0.005$) but not in the caring groups.

Caring characteristics were also studied by Burton, Haley and Small (2006) who identified their usefulness for assessing responses of bereaved older people to sudden spousal loss. Depression level increased significantly over time in the unexpected death group ($p = 0.001$), and remained stable for high stress, low stress, and non caring groups (pre-loss to 18 months post loss). However, there could be a number of other caring characteristics that influence bereavement response that were not included in the analysis, for example, length of time caring. Results support the importance of considering caring characteristics as an important aspect of the context within which bereavement is experienced, and may also be useful when assessing the bereaved.

A longitudinal study by Ott et al (2007) examined grief responses in older adult spouses to identify patterns of change and whether clustered patterns of change differ in demographic, experiential and clinical variables. This well designed study, carried out longitudinally as part of the Yale Bereavement

Study, found significant changes in grief, depression and mental health scores over three waves of interviews ($p < 0.001$). Scores for grief and depression declined ($p < 0.001$) and mental health scores improved ($p < 0.001$), however physical health scores did not change. Three clusters of grief symptoms were identified: resilient; common; and chronic. The chronic grief cluster had the highest levels of grief and depression and poorest mental health. There were significant differences between clusters for cause of spouse death: sudden death accounted for 37.5% of chronic grief cluster; 10.4% in resilient cluster; 18.8% of common grief cluster ($p = 0.022$). There were also significant differences in perception of being prepared for the death between the clusters with the chronic grief cluster being least prepared ($p = 0.006$). In addition, differences were found in perceptions of how peaceful or violent the death had been. The resilient group had experienced the death of the deceased person as most peaceful ($p = 0.001$). There was no significant difference in the quality of marital relationship between groups, though level of spousal dependence differed significantly with those who suffered from chronic grief having been most dependent ($p < 0.001$). Across the grief clusters, the four most commonly experienced effects were: yearning and longing; life as empty or meaningless; anger or bitterness; difficulty moving on. This study aids identification of those likely to be at risk of developing complicated grief and highlights diversity in the adjustment process of older spouses. It gives indication of the characteristics of people who may benefit from interventions that address grieving difficulties.

More recent research focuses on the resolution of regrets in the bereaved and the role in adjustment to loss in carers of terminally ill people (Torges, Stewart and Nolen-Hoeksema 2008). Participants were recruited via hospices potentially reducing the generalisability of the results. In addition, older people made up only a small proportion of the sample studied (22%) and findings did not provide adequate inter-age group analyses. Validated measures were used to assess depression, rumination, and well being and anxiety. However, the measure of regret resolution was identified by the authors as simplistic, and there was no assessment of complicated grief. The older participants were, the more likely they were to have resolved their regrets ($p < 0.05$). 64% of older adults resolved their regrets, 52% of middle

aged, and 39% of younger adults. In general, people who resolved their regrets experienced fewer depressive symptoms, though across all participants depressive symptoms decreased over time. Higher pre-loss depression scores indicated higher post loss scores, and women had more depressive symptoms. Those with unresolved regrets decreased in depressive symptoms from 1-6 months, but did not further decrease to 18 months. Those who resolved regrets did not decrease in depressive symptoms from 1-6 months, but did decrease to 18 months.

Torges, Stewart and Nolen-Hoeksema (2008) also found that well being post bereavement increased over time and better health pre loss predicted better health post loss. Interaction of regret resolution and time was a significant predictor of change in well being over time ($p < 0.001$). Participants' level of anxiety decreased over time, though being more anxious pre loss led to higher levels of anxiety post loss. The interaction of regret resolution and time was also a significant predictor of anxiety over time ($p < 0.05$). In a similar light, higher level of pre loss rumination led to higher level post loss. People who resolved regrets had lower levels of rumination than those who did not ($p < 0.001$). This last group of results are not age specific, however, may be considered in view of older people being more likely to have resolved regrets.

Using a questionnaire survey Elklit and O'Connor (2005) examined the frequency of post traumatic stress disorder (PTSD) and associated symptoms in older people in relation to experiences of recent loss, demographic variables, previous trauma, social support, predictability of the loss, PTSD and symptom levels. However, generalisability was limited by a moderate response rate, losses to follow up, no control group, and gatekeeper access to participants. The self report method may also be a potential bias in the study. Experiences related to the loss and that may be relevant to the authors' definition of PTSD were loneliness, yearning, having seen the spouse's suffering, suddenness, fear of the future, helplessness, and emptiness. The study found that PTSD was a common phenomenon reported by the elderly bereaved in the study, developing in a quarter of the respondents. The most pronounced symptoms were depression and sleep difficulties, and these remained consistent from 1 month post loss to 6 months. Stability of distress

symptoms correspond with other studies and may indicate a slow recovery process or a process of becoming chronic. The relatively high level of social support reported had little impact on reducing symptoms.

Lack of expressive ability, fear of own death or illness, and helplessness at the time of the death predicted 90% of the degree of traumatisation of the older people in the study. No difference was found in traumatisation at one month and six months. Length of terminal illness and forewarning were not effective predictors of traumatisation or psychological distress. However, prolonged illness of the spouse resulted in high level distress. At one month post bereavement 27% of participants met the four criteria for PTSD as described by the authors: A2 criteria (used to indicate subjective emotional response to a stressor [Bedard-Gilligan and Zoellner 2008]); intrusion; avoidance; hypervigilance, and 16% showed a subclinical level. At six months, 17% satisfied the four criteria and 28% had a subclinical level (Elklit and O'Connor 2005). The study provides tentative evidence for the intensification of efforts to assess bereaved older people as part of the preventative work done by healthcare workers.

Research on psychological resilience by O'Rourke (2004) has found significant association with well being in widowed women, and it is more influential on response to loss than factors like years married, preparation for the death and length of time widowed. Socio-demographic variables were also shown to have no effect on life satisfaction, however, they were associated with psychiatric distress. Commitment to living was identified as a resilience factor, and contributed significantly to observed variance in psychiatric distress. Data were collected from participants internationally online. The average age of participants was 60.62 years, indicating that older widows were excluded by the methods. In addition, data was only collected at one time point which may have differed between participants, so causal conclusions cannot be made. However, the study reinforces the idea that positive resilience strategies in widows benefit their health and well being.

Hagedoorn et al (2006) also explored differences in distress between widowed older people and married contemporaries as part of a larger population based

study of ageing. Validated measures and detailed statistical analyses were carried out. A significant effect of marital status was found, but none of the analyses showed a significant effect of gender or a significant interaction between marital status and gender. Overall married persons were less distressed than single persons ($p < 0.001$). Differences in distress (higher score, more psychological distress) were qualified by partner loss and recent bereavement ($p < 0.001$). However, always single groups reported less distress than all other groups (mean distress measure 8.8, SD 4.6). Only the short term (mean 14.4 months, SD 7.8) and medium term (mean 12.3 years, SD 6.9) widowed but not the long term widowed (mean 10.8 years, SD 5.8) reported more distress than married participants (mean 10.2, SD 4.6). Married people who felt under-benefited in their marriage reported even higher levels of distress than long term widowed. Short term widowed people (<2 years) showed the highest levels of distress.

The findings from the studies above highlight vulnerability in widowed older people to psychological and mental health difficulties in the short term post bereavement. Four main factors that may affect response to bereavement in older people are indicated: gender; caregiving status prior to the death; resilience; and marital status. There is evidence to suggest that widowed men may be more likely to become depressed following a family bereavement than women. This may be due to the loss representing greater change in social support availability for men. However, church membership, though not necessarily a proxy for church attendance, may be a predictor of lower depression scores in men. The connection with the church may have a stress reducing function.

The death of a spouse for family carers who were burdened by their roles may represent reduction in stress and no further pressure on their ability to cope. The death brings an end to the ill person's suffering as well as an end to the demanding caring role. In addition, the death is often predicted giving the caregiver time to prepare for the loss, and the existing support network of the carer is likely to be there to support when the death occurs. Healthcare professionals who come into contact with bereaved carers may develop

opportunities to explore the caring experience and listen and support accordingly.

Papers in the review provided some evidence for a common, or resilient, grief pattern characterised by elevated grief and depression levels shortly after loss that decrease over time. Additionally, life experience associated with age may offer resources for the resolution of regret which is associated with greater adaptation. Older people may be more likely to have resolved their regrets, though no relationship has been identified between age and overall adaptation. Conflicting influences of aging on bereavement, for example, multiple bereavements, reduced physical and emotional resources, and quality of the social network influence response and create difficulties in identification of determinants of adverse response. The resilient group maintain their adjustment over time indicating little or no need for professional intervention and provision of opportunities to speak about life with the deceased and their loss may be all that is required to foster resilience. However, a minority of bereaved older spouses experience complicated grief and the ability to identify these individuals early in bereavement may lead to decreasing morbidity and improving quality of life.

In general, there is some evidence indicating that married people are less psychologically distressed than single people, and partner loss and recent bereavement contribute to more distress in those living alone. However, in the long term widowed people are no more distressed than those who remain married. Widowed people appear to adapt over time to the single role and may reach a level of well being above that of people who report dissatisfaction in their marriage. Adaptation and coping may be different for all older people with some, for example, moving on to new relationships or challenges while others cope by living with their memories and are contented to be alone.

The review also acknowledged research linking bereavement response to PTSD. Psychological symptoms experienced by older people post bereavement may be consistent with a diagnosis of PTSD. Intensification of efforts to assess bereaved older people is again indicated. However, the

appropriateness of looking for PTSD symptoms to all older people post bereavement needs careful consideration.

Loneliness and feelings of isolation are frequently highlighted in the qualitative research literature as particularly dominant experiences for bereaved older people. However, assessment of the quality of studies was challenging when, in many published studies, the methods are provided in brief and emphasis is given to results. Subjective assessment (see Table 3) was made based on the availability of an audit trail in the paper leading the reader through the methods to logical results and conclusions (Appendix 1, provides more information on quality assessment).

Loneliness has been described in the short and longer term, particularly for those bereaved of a spouse or partner (Costello and Kendrick 2000, Anderson and Dimond 1995). Loneliness is accentuated by daily reminders of the dead spouse, anniversaries of the death, having to learn to do tasks previously carried out by the partner, and socialising as a single person (Anderson and Dimond 1995). In addition, examination of widowhood in older people, indicates similar physical and psychological symptoms in both 'senior' widow(er)s (aged 60-74) and 'elderly' widow(er)s (aged 75-90). However, loneliness was the most frequent difficulty affecting 60% of elderly widows and 23% of senior widows (Hegge and Fischer 2000). Loneliness, previously viewed as an aspect of grief, has also been found to be part and parcel of the social experience of ageing (Costello 1999a). Loss was recognised as wider than loss of the partner extending to feelings of being socially disenfranchised. In addition, when it is not regarded as a separate entity from grief there may be difficulty in adapting to the situation and challenges for the wider social network and health and social care service providers (Costello 1999a).

A further study found two core concepts describing the structure of the lived experience of grieving a loss: 'aching solitude amid enduring cherished affiliations' and 'serene acquiescence with sorrowful curtailments' (Pilkington 2005). These statements, though provided in inaccessible language, seemed to demonstrate the loneliness of older people following losses in their lives, even though they live with others in a care home. It also demonstrates

continuing connections with the deceased who live on in the lives of the bereaved, a concept further explored in section 2.1.4.

Quantitatively, a study measuring outcomes for older widows and widowers followed up longitudinally found that loneliness scores after the death of a partner are significantly higher than before. However, social loneliness scores may remain unchanged while emotional loneliness scores are significantly increased (van Baarsen et al 1999). Contributing factors to loneliness post bereavement may be less intense disease progression in the person who died, poorer health, attaching more importance to receiving support, being more socially anxious and having had less support during the marriage. In addition, higher levels of loneliness were found in those who talked about the death more often, and attached less importance to contact with others. Predictive factors for emotional loneliness in the bereaved spouse include being unable to predict the death and poor physical condition. Poor physical condition was also predictive of social loneliness and social anxiety (van Baarsen et al 1999). The study underlines the need to understand coping in widows and widowers and how this influences their support needs. It also highlights the vulnerability of bereaved older people to emotional isolation. Validated measures were used in this study though methods described were complex and lacked clarity.

2.1.3 Changed relationships with self and others

The material reviewed in this section highlights the diversity of bereavement responses and experiences and provides an additional perspective on bereaved older people's redefinition of their sense of self and their role in society. Two of the studies included in this section have also been included in section 2.1.4 on the closely related theme of continuation of the bond with the deceased.

Following bereavement, relationships between family members, friends and others often change to accommodate the loss and those who have suffered most from the loss. The bereaved may accommodate the dead person in their lives in a variety of ways that either facilitate or not, alterations to social structures. This is illustrated in Rory Williams' book that reports the results of

a qualitative interview study with Aberdonians aged over 60 years (Williams 1990). In general, bereavement was constructed around the situation of the dead and the situation of the bereaved. The situation of the bereaved was characterised by a tension between replaceable and irreplaceable aspects of loss. The loss of the person was seen as non-negotiable and irreplaceable, though acceptance was often painful and protracted. Secondary losses that accompanied the death, such as social connections and opportunities for social participation were seen as difficult but ultimately replaceable. Emotional work, investment in new relationships and in making changes to existing relationships by the bereaved themselves and those around them was necessary to find meaning in the death and in continued life. Relationships are often renegotiated in families for mutual benefit, and new commonalities and sources of support found with friends.

Causal attributes for their husbands' deaths and the role this plays in widows' understanding of being bereaved were examined by Bennett (2004). Interview analysis found that women commonly attribute their husbands' deaths to health related and medical contributory factors, lifestyle, and *magical explanations* (covering lay understandings). Attributing explanations for the death formed part of the widows' narratives and their personal stories of losing their husbands. This is a key part of the search for meaning in the death and possible reasons for the phenomena are looking for someone to blame, needing to determine whether doing something differently may have meant that the spouse would still be alive, and to make sense of the death. Widows use attribution to form narratives of their husband and the death to internalise the meaning and to provide explanation to others. The author concluded that making attributions is part of the course of normal bereavement and is not necessarily negative, and does not predict future misery.

A study by Hockey, Penhale and Sibley (2001) aimed to describe the practical and emotional challenges of sustaining a meaningful life as the surviving spouse and focused on the survivors' use of public and private spaces. Twenty older people bereaved for more than eight months were recruited to examine use of spaces. Data analysis revealed the main theory of widowhood to be

changes in the embodied experience of space in terms of both gains and losses. Many participants experienced minor changes in their home and social lives, though these were often part of a major shift in the experience of living alone. For example, meal times and planning and taking holidays were when more evident changes arose. This led to social isolation and loneliness being seen as permanent features in the widow(er)'s life. The type, position and shape of the home itself often presented a problem for the surviving spouse. Security and isolation were concerns described by widow(er)s living in their own homes in quiet suburbs. In describing changes to their social lives, bereaved spouses in the study described new unwritten rules for visiting family and the development of reciprocal relationships. In addition, interviewees who experienced their social life as difficult often saw their health as a legitimate reason for going out, for example, to attend medical appointments. This became more evident when they lived alone, and interdependent family relationships became crucial. Hockey, Penhale and Sibley (2001) also found that the widow(er)'s relationship with space often depended on the dead partner's dying trajectory. Those whose partners died after a spell of illness were more likely to have gone on to use space in a more rewarding manner. Freedom was often described as a gain, while the sense of being a couple had been lost. However, this sense of partnership may have been lost prior to the death due to the illness.

Bennett (2005) developed a theme from her previous research (Bennett 2004) that focused on widowers' discourses about the value of their lives and decisions to continue living after their wife had died. A grounded theory methodology was used. Sixty participants aged between 55-98 years (mean 79), and widowed between 3 months and 25 years (mean 7 years) took part in interviews. The main finding was that a third of widowed men openly discussed the value of their lives. Specific themes about decisions to continue living arose. Many expressed carelessness about life and the decision to live. The men thought about suicide and took actions that expressed lack of concern about themselves. However, men were stoical and described keeping going for others and carrying on against the odds. The research also found that age and status as widowed led men to consider their mortality. It was described in terms of their impending death, their longevity, and often

multiple losses of friends and associates. Several factors explained the men's decision to live demonstrating diversity of experiences. Survival may be dependent on an explicit (or inexplicit) discourse about the meaning of life that is part of the decision making process. For some there may of course be no explicit discourse and just a half way point between choosing life and committing suicide. The findings of this study may reflect widespread concerns among widowers and is viewed by the author as important because of the cultural reluctance to discuss suicide and political concern to reduce preventable deaths (Bennett 2005). These men may be unusual in that they had not died before or soon after their wives and had not remarried.

A further area of study that is relevant to older people describes the experiences of sufferers of dementia when they lose someone close. The ability of the bereaved person who suffers from dementia to understand and accept the death is often compromised. A qualitative study by Grief and Myran (2006) reported a case series of older adults with cognitive impairment and categorised bereavement related distress. They found that constantly reminding people of a death was distressing to the bereaved person, the family and health and social care staff involved in the care of the bereaved person. They further found that families needed support to cope with constantly revisiting a death with a cognitively impaired person. Treatment for the cognitive impairment with medications was used with varied success and multi-dimensional treatment plans were recommended. This study lacked description of methodology and methods and was therefore assessed to be of poor quality. However, it did raise issues of the changed family dynamic, complex support needs for the bereaved person with dementia and the wider family, and the emotional burden on the bereaved person with dementia, the family and care staff.

2.1.4 Maintaining continued bonds with the deceased

The review of research into bereavement and older people has found outcomes in qualitative studies that emphasise the existence of continued relationships with the deceased. However, no empirical studies supporting the theory exist and any support for continuing bonds comes mainly from the counselling and therapy literature. Anderson and Dimond (1995) examined

the experiences of older people bereaved for up to two years and found that people took solace in memories of their spouse and coped by managing reminders of the loss and maintaining a continued relationship. Hegge and Fischer (2000) also found that widows took refuge in their memories and 70% of elderly widows and 50% of senior widows had vivid dreams or sensed their spouses' presence. Additionally, in their study of the challenges of sustaining a meaningful life as a widowed spouse Hockey, Penhale and Sibley (2001) found that use of space depended on a number of issues including the continued relationship with the deceased. The influence of the dead spouse lay within the home environment and the places formerly visited as a couple, and was key to how the widow chose to use and change the same familiar spaces. The dying trajectory of the husband or wife was also important, and the research found that a widow whose partners' death was predicted and took place after a spell of illness was more likely to use their space in a rewarding manner.

Bennett and Vidal-Hall (2000) explored the role narrative may play in accepting widowhood through interviews with 19 older women. In all but one interview the death was identified as fundamental to the experience of bereavement. The main finding was that forming narrative of the death played a role in committing events to memory, maintaining an ongoing relationship with the deceased, and preparation of a story for public recounting. The purpose of narrative proposed by the researcher was that it contributes to the identity of the widow in the past and at present, defines them as wife, carer or widow, and may provide comfort while helping to make sense of the event. Continuing the bond therefore seems integral to the bereavement experience. In addition, Costello (1999b) and Costello and Kendrick (2000), in studies of grief resolution, found that this inner representation and development of a dialogue with the deceased was part of the widow's coping strategy. The work concluded that palliative care nurses may have a supportive role for relatives in the construction of these stories.

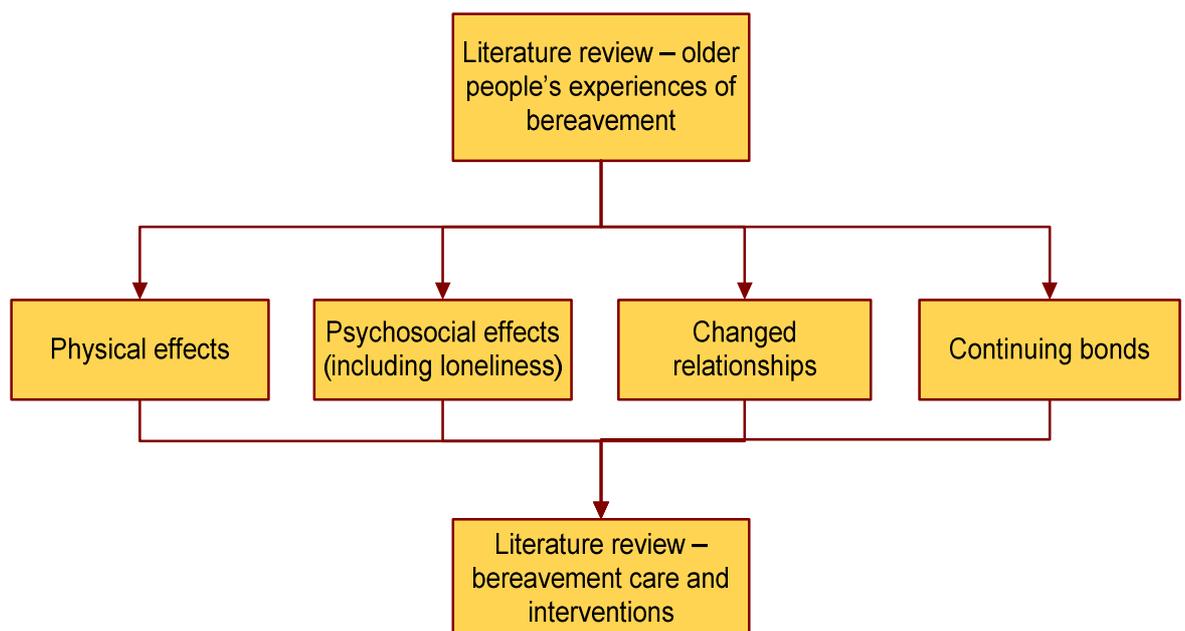
2.2 Bereavement care provided by healthcare services

Many people begin to experience bereavement while in the company of healthcare professionals, often in unfamiliar settings where consistent

bereavement care services are unavailable (Cobb 2008). However, Parkes and Prigerson (2010) believe that most doctors and nurses would consider bereavement care to be part of their role, and that they are in a good position to provide information and emotional and practical support. In addition, the importance for relatives of what happens at the time of bereavement has been stressed because poor communication, frustration and distress are remembered (Relf 2008). Services for the bereaved, in general, stop soon after the death with the exception of palliative care and community provision. However, simple follow up interventions like phone calls, letters and domiciliary visits may be all that is needed to see people through difficult transitions (Cobb 2008). Support is usually appreciated and allows those who may suffer most to be recognised and directed to specialist help (Parkes and Prigerson 2010). In this section of the review, research about bereavement care and specific interventions is amalgamated and interpreted.

Up to this point specific experiences that may be common for older people as a result of becoming bereaved, both in the short and long term have been identified. This leads logically to reviewing research on services and interventions designed to address bereavement care needs. Figure 3 (below) illustrates the progress of the review to this point.

Figure 3. Literature review flow chart



Extending the review in this way informed the development of the guidelines for bereavement care for older people that was a main aim of the empirical research reported in this thesis. Research was identified in the three settings of interest for the study and these were used to group studies and report findings:

- bereavement care in community nursing and general practice;
- bereavement care in hospital wards;
- bereavement care in care homes.

Sub-themes were identified under each heading.

Some examples of independently provided services and some intervention studies are included as they may also inform service development by providing useful evidence for or against adopting the intervention in practice. In addition, some examples of studies based in palliative care and hospice provision are included as bereavement care is well established in these areas and may inform service development in mainstream services. Qualitative, quantitative and mixed methods studies are included.

The number of papers that met inclusion criteria was small and only two studies have been identified that exclusively reported on a service provided for older people (Katz, Sidell and Komaromy 2000, Lyttle 2001). In general, bereavement care services are provided for the adult population as a whole with some services being for specific groups, for example, parents who lose a child or who suffer perinatal loss, those whose partner dies of HIV or AIDS. The result is that this review includes studies of bereavement care services and interventions for all adults, though an attempt has been made to group studies that may be particularly relevant to services for older people.

2.2.1 Bereavement care in community nursing and general practice

Publication information for the studies reviewed in this section is provided in Table 4 overleaf. One study particular to the care of older people explores the perceptions of community nurses about providing bereavement follow up (Lyttle 2001). This study provides a reference point for examining the views of district nurses in the main empirical study described in this thesis. Other research based in primary care services explored the role of the district nurse

Table 4. Included studies – community services

Author	Year	Publication	Title	Database	Quality
Booth, R.H.	1990	Grey literature (A research report located in the library of Balfour Hospital, Kirkwall, Orkney)	Cancer Care in the Community.	Grey literature	Fair
Carlsson, M.E. & Nilsson, I.M.	2007	Palliative and Supportive Care 5: 397-404	Bereaved spouses' adjustment after the patients' death in palliative care	Medline	Poor
Lyttle, C.P.	2001	British Journal of Community Nursing 6(12): 629-635	Bereavement visiting: older people's and nurses' experiences	Cinahl, ASSIA	Good
Grimby, A. & Johansson, A.K.	2008	American Journal of Hospice and Palliative Medicine 24(6): 475-478	Does early bereavement counselling prevent ill health and untimely death?	Medline	Good
Birtwistle, J., Payne, S., Smith, P. & Kendrick, T.	2002	Journal of Advanced Nursing 38(5): 467-478	The role of the district nurse in bereavement support	Cinahl, Medline	Fair
Saunderson, E.M. & Ridsdale, L.	1999	BMJ 319: 293-296	General practitioners' beliefs and attitudes about how to respond to death and bereavement; qualitative study	ASSIA	Fair
Peters, H. & Lewin, D.	1994	Intensive and Critical Care Nursing 10: 257-264	Bereavement care: relationships between the intensive care unit and the general practitioner	Medline, Cinahl	Fair

in the support of bereaved relatives (Birtwistle et al 2002), and general practitioners' responses to bereavement (Saunderson and Ridsdale 1999). Two studies examined services for relatives bereaved of someone who had been cared for by a palliative care or cancer services team (Booth 1990, Carlsson and Nilsson 2007). The studies are included because both report bereavement follow up in general practice and community nursing and are believed to be relevant sources of information for the current study. Grimby and Johansson (2008) also provided evaluation of an intervention for bereavement care within community services. A further study in this section examined communication between a hospital intensive care unit and GPs in the area as regards bereaved relatives, from the point of view of GPs (Peters and Lewin 1994). Four main areas are covered by the literature reviewed for community based services: activities carried out by services to address the needs of the bereaved; communication between services about the bereaved; perceptions of providing bereavement care; and bereavement care interventions.

Activities carried out in healthcare services for the bereaved

Activities undertaken to address bereavement needs are, in general, viewed in the literature as a small part of roles that are varied, complex and time pressured. Booth (1990) described in detail the roles of district nurses, general practitioners, and the clergy, in terms of providing terminal care at home. The study was designed to provide an overview of terminal care services and interactions between service providers that would be a base from which to develop relevant training strategies. Bereavement is included in the exploration as one aspect of the complex range of needs addressed by staff. Bereavement care was seen by nurses to be a logical extension to their role with dying patients and their families in the community. Nurses built up a relationship with families over time that enabled them to help families to be prepared for the patient's death. Because of this intimate relationship, they felt that they needed to be there after the death to provide support. Post bereavement visiting, phone calls and attending funerals were common activities. The number of visits and the length of time the visiting continued for depended on the circumstances of the families. Those with a supportive

network around them did not need such an intense service as those whose loss meant that they were alone.

The same study (Booth 1990) identified that some GPs saw bereavement care as part of their role as a family doctor, though most viewed symptom control as their main input to terminal care. Those who provided support for the family after the death would visit in the early days, sometimes visit again, and would subsequently invite family members to come to the surgery. In total three or four contacts would be made. At one visit an assessment is made and what happens next is dependent on the outcome. The study is unclear about the contents of the assessment and the flow of actions that could result. Doctors describe using contact time with the relatives to reassure them that grief is a normal process (Booth 1990).

Birtwistle et al (2002) surveyed a sample of 522 qualified and unqualified district nurses using a postal questionnaire that included a section on usual care provided to the bereaved at their practice. 324 responses were received (62%), and extensive information about current practice was collected. Most nurses (93%) thought they should visit relatives when a patient they had been caring for died, and 82% thought they should maintain contact. However, only 32% always visited and 41% frequently visited. 56% thought they should visit in the first three days, and 84% in the first week. When the deceased was not on their case list 19% thought a visit should be their duty, and 24% thought the family should be contacted to ensure they were coping.

The study by Birtwistle et al (2002) further found that 78% of nurses said that the length of time that contact was continued was tailored to peoples' needs. When visiting, assessment of the relative's ability to cope was made by 94% of nurses and assessment of suicidal ideation was made by 37%. No information is provided in the paper about assessment strategies and objectives of assessing. The visit was also an opportunity to provide information on practical things (63%), bereavement organisations (53%), and emotions (45%). Ten percent of the sample considered bereavement visiting to be intrusive. Logistic regression indicated that district nurses who are qualified to diploma or degree level are more likely to visit the bereaved.

Interest in bereavement was also an important factor in whether or not the nurse visited. The authors recommended further exploration of the issues raised; the development of guidelines for best practice; improved information availability for the bereaved; and reassessment of practitioner training in bereavement care.

Communication between services about the bereaved

Examination of communication about bereaved relatives between staff providing services and between service sectors was a key topic of interest for this project. A study by Peters and Lewin (1994) has explored communication between a hospital intensive care unit and general practice from the perspectives of participating GPs. The study found that 30 (44.8%) GPs could recall a patient dying in the local ICU, and for these the mean length of time taken for them to be notified of the death was 4.3 days. Half the GPs who had a patient die in ICU said that a relative had informed them and 22 of the 30 said that this caused them concern. All but one GP would like to be told within 2 days and 94% wanted to be told by a member of ICU staff. GPs found it useful to talk by phone to staff and thought that it facilitated early follow up of the relatives. However, bereavement care was low priority for GPs and they thought that hospital services should be enhanced. The author recommended the development of a policy for sharing information about bereaved relatives and concluded that follow up appointments for bereaved relatives with the consultant may be one way to address relatives' concerns. Additional training for staff was also recommended. This study however, was unclear in its initial focus and it appears that the results determined the aims. Its generalisability may be limited as only the views of a small sample of GPs in one area of London were included.

Perceptions of bereavement care

Lyttle (2001) studied the perceptions of community nurses about providing a bereavement service to older people, and of older people about receiving the service. Twenty community nurses took part, including 12 health visitors, 7 district nurses and one triple duty nurse. Two common themes arose for nurses and bereaved older people: relationships between nurses and patients' relatives; bereavement care practice. Both parties thought that bereavement

visiting was appropriate if there was a rapport between the nurse and the family. Nurses thought that a bereavement visit should never be a first visit. The nurse was often seen as a friend of the family and a continued relationship that was flexible to the needs of the bereaved relative was valued. The practice of bereavement visiting was often compromised because of time constraints for the nurse. Concerns were also raised about the lack of clarity regarding the desired outcomes of bereavement visiting and having no way of measuring impact. Half bereaved older people in the study reported visits having beneficial effect and half said there was no effect. Nurses also said that their personal experiences of bereavement influenced their practice, though this is not described in the quotations included in the paper. There was also acknowledgement that at times the organisation of care was such that a bereaved person received no follow up, and nurses saw this as a failing of the system. Additional concepts identified were organisational issues for nurses in terms of providing a client led service, and managing competing demands on their time. There was also recognition of the need for training in bereavement care. For the bereaved, perceptions of their coping was mixed and they identified difficulty in knowing whether the nurse's support was helpful. The study was a useful addition to the literature that identified bereavement care practices of community nurses in an area of Scotland.

Using a qualitative grounded theory study design, Saunderson and Ridsdale (1999) investigated perceptions of 45 GPs when notified of a death, their relationships with bereaved relatives, and difficulties in managing bereavement. They found five main themes:

- GPs described a sense of loss themselves when a patient died. They blamed themselves when expectations of patients and relatives differed from reality, though they believed that their long standing relationship with relatives was protective.
- GPs' long term relationship with patients allows them to be aware of physical, psychological and social influences on a person's health and well being, including response to bereavement.
- Attitudes and beliefs of GPs were based on personal rather than professional experience of bereavement, and they felt that their training

did not prepare them for dealing with bereavement. The medical mind set was a barrier to interaction with the bereaved.

- GPs take different approaches towards contacting the bereaved, and making contact depended on their relationship with the family. In addition, cases were considered on their merits and visits were more likely if the death had been sudden or traumatic. Most visited, sent a card, or phoned relatives. They described having a desire to be empathetic, sympathetic and compassionate.

Additionally, the study by Peters and Lewin (1994) found that bereavement care was a low priority for GPs taking part in the study. It was their opinion that hospital services should be enhanced to provide follow up of relatives. However, clinical staff surveyed in hospital believed that giving more time to bereaved relatives would put pressure on patient care.

Bereavement care interventions

This section provides examples of intervention studies carried out within community services to address the needs of the bereaved. Carlsson and Nilsson (2007) tested a follow up strategy for spouses whose partner had died of cancer. The intervention consisted of a nurse visit to the identified bereaved partner 1, 3, and 13 months after the loss. Topics covered during the visit were the partner's death, the surviving spouse's health, grief reactions, socio-economic status, exercise and lifestyle, and occurrence of hallucinations. Validated grief measurement tools were used to quantify outcomes. Bereaved spouses felt fairly healthy during the study. In general, sleep difficulties declined during the year but there was no decline in musculo-skeletal pain. The intensity of grief reactions diminished significantly during the year for the whole sample, though women had a higher level of grief at 1 month and 13 months than men. During the study half the 45 participants had experienced post bereavement hallucinations. At 13 months all expressed interest in current events, most had friends, 16 had new friends, and five said their faith had increased. However, most reported that they hadn't changed their lifestyle. At 13 months when 42 participants remained in the study sample, 93% thought they had adjusted well and 83% had positive outlook.

Due to the study design used by Carlsson and Nilsson (2007) it is unclear what the effect of the visits was on bereavement outcomes for the participants. Had there been a control group, comparisons could have been made between those who had the intervention and those who did not. The changes over time reported in the study could have been the result of chance or could reflect the natural process of grieving. These methodological difficulties mean that this study has been judged to be poor quality. However, running a randomised controlled trial of a bereavement care intervention carries ethical dilemmas for researchers regarding provision of additional support to an intervention group while a control group gets no support or usual care which would be much more ad hoc in nature.

Grimby and Johansson (2008) have also studied the impact of an intervention for bereaved relatives, but used a case control study design. Comparison was made between a group of widowed people receiving support and a group of married people of the same age. Widowed participants were offered physical examinations by a physician and psychological support 1, 3, and 12 months after loss. Data were collected at 1 month with a quality of life questionnaire, and at 5 and 8 years the numbers of days of hospital care and mortality rates were gathered. Quality of life was lower among recently bereaved than married controls and those never married, but similar in three from four dimensions to divorcees. No significant difference was found between the bereaved group and married group in consumption of care in the four year period before baseline data collection. There was also no significant difference in number of days of hospital care or survival time five and eight years post baseline observation. Lower quality of life in widows and divorcees may be due to recent stressful events, and the lack of significant bereavement effect on mortality may be due to frequent contact with a health care professional. However, bereavement effect on mortality is small and it may need a much larger sample size to show any changes over time.

2.2.2 Bereavement care in hospital wards

Table 5 overleaf lists the studies included in this section of the review that reflect the care of bereaved relatives who have contact with hospital services. Four subthemes identified were: current bereavement care practice;

Table 5. Included studies – hospital services

Author	Year	Publication	Title	Database	Quality
Parris, R.J., Schlossenberg, J., Stanley, C., Maurice, S. & Clarke, S.F.J.	2007	Emergency Medical Journal 24: 339-342	Emergency department follow up of bereaved relatives: an audit of one particular service	Cinahl, Medline, Embase	Poor
Holman, C., Meyer, J. & Davenhill R.	2006	Journal of Social Work Practice 20 (3): 315-328	Psychoanalytically informed research in an NHS continuing care unit for older people: exploring and developing staff's work with complex loss and grief	Cinahl	Fair
Olsson, M.	1997	Social Work in Health Care 25 (1/2): 117-130	Social support in bereavement crisis: A study of interaction in crisis situations	Cinahl, Medline	Poor
Peters, H. & Lewin, D.	1994	Intensive and Critical Care Nursing 10: 257-264	Bereavement care: relationships between the intensive care unit and the general practitioner	Medline, Cinahl	Fair
Milberg, A., Olsson, E- C., Jakobsson, M., Olsson, M. & Friedrichsen, M.	2008	Journal of Pain and Symptom Management 35 (1): 58-69	Family members' perceived needs for bereavement follow up	Medline	Good
Kaunonen, M., Tarkka, M-T., Laippala, P. & Paunonen-Ilmonen, M.	2000	Cancer Nursing 23 (6): 483-491	The impact of supportive telephone call intervention on grief after the death of a family member	Medline	Good
Ellison, N.M. & Ptacek, J.T.	2002	Journal of Palliative Medicine 5 (1) 49-55	Physician interactions with families and caregivers after a patient's death: current practices and proposed changes	Medline	Fair

understanding the interaction between hospital staff and bereaved relatives; family members' needs; and interventions to address needs.

Current bereavement care practice

The continued development of a follow up service for bereaved relatives at an emergency department was reviewed by Parris et al (2007). Over a four year period (2001-2005) letters inviting 1,179 bereaved relatives to attend a follow up meeting were sent. 478 (41%) replied, 14% accepted the offer of a meeting with the consultant to discuss issues about the death and 27% declined. The relatives who accessed the service wanted answers to specific questions, for example, cause of death (75%), distress experienced by the patient (19%), need for screening for themselves or other family members (7%). At 81% of meetings information was provided about follow up bereavement support available in the voluntary sector or relatives were directed to their GP. 21 (13%) were advised to have medical follow up. The study emphasised relatives' need for the opportunity to obtain further information about the death. The intervention was not labour intensive for hospital staff and did not need specialised staff. The authors indicated that it was something that may be relatively easily done for bereaved relatives in other areas of health care. However, there was no measure of the effectiveness of the service or how it impacted on the grief reaction of the relatives.

Ellison and Ptacek (2002) surveyed hospital physicians to explore current practice as regards bereavement follow up to inform the development of a comprehensive bereavement programme. A postal questionnaire survey was sent to 286 physicians, 143 (50%) responses were received and 119 said that they deal with patient deaths. This was the sample on which analysis was carried out (41.6% of original sample). The majority did not send a condolence card, visit the relative or attend a service. After an inpatient death phone calls were made by 40% of physicians more than 50% of the time. For outpatients no phone call was made in 38% of cases. However, further analysis showed that the response pattern for inpatient deaths did not differ significantly from that for outpatient deaths. 48 (40%) of physicians sent a condolence note after either inpatient (46%) or outpatient deaths (34%), or

both. Hand written notes were used most often (65%). The number of years a physician had been at the medical centre was significantly related to contact after both inpatient ($p < 0.01$) and outpatient deaths ($p < 0.01$). Physicians who had been at the centre for the least amount of time were less likely to make use of both letters and phone calls after deaths. There was no relationship between years in practice or number of deaths annually and physician activities regarding bereaved relatives. Of 107 physicians 36% suggested meeting with the family after the death of an inpatient, and 27% after the death of an outpatient. Actual meetings occurred in 11% and 17% of cases. 46% had suggested bereavement groups to relatives. When asked whether a bereavement programme at the hospital would be useful 71% thought it would be helpful provided bereaved relatives and carers could be identified. The findings of the study support increasing the level of service to bereaved relatives and carers.

Interaction between hospital staff and bereaved relatives

Two studies relevant to response of hospital staff to bereaved relatives, patients and colleagues have been reviewed in this section. Holman, Meyer and Davenhill (2006) explored psychological and social influences on care delivery that staff have to negotiate in order to cope with loss and grief in an NHS continuing care ward. The aim of deciphering the factors that play a part was to inform and improve team working and the psycho-social aspects of care. Participants were a psychologist, an occupational therapist, 13 registered nurses, and 13 auxiliary nurses. The patients were described as a group of highly dependent elders being cared for by a very ethnically diverse group of care staff.

Reflection with the group and observation found that staff often glossed over elements of emotionally demanding work. There was a strong emotional component to entering, living and dying in a continuing care unit that staff linked with loss. Bereavement care for residents and relatives was found to be difficult and stressful and care staff found they were often criticised for not providing enough emotional support. Emotions are difficult for care staff to address and they were found to use routine to prevent residents expressing themselves. The authors promote using psychological and sociological

approaches with care staff to develop a fuller picture of complex work situations. Exploration of hidden aspects of experiences can help service providers and staff to understand and work positively with emotions. The outcome may be more positive engagement with patients' and relatives' emotional needs and in particular to address issues of loss and grief (Holman, Meyer and Davenhill 2006).

In order to gain better understanding of the interaction between bereaved relatives and hospital staff at the time of bereavement, Olsson (1997) carried out a qualitative research study with relatives of patients who had died in a coronary care unit. Eighty-eight relatives were invited, 60 (68%) agreed to take part (32 spouses, 28 children). The study found that the crisis situation had an impact on relatives' support needs. Difficulties were identified when the relatives had been unprepared for the death and had been unable to be with the patient when he or she died. When events did not take their desired course emotional support became crucial, particularly when a relative was alone. All members of the family can be distressed and as such may be unable to support each other. Each member may also have different needs for professional support. It was also found that information given at that time was difficult to comprehend and, though important, its support quality was compromised.

Olsson (1997) identified four patterns of interaction with hospital staff: usual level of dialogue with staff maintained; relatives were overly aggressive, demanding, or despairing; inactivity or surrendering to being led by staff; and need to be left in peace. However, for each pattern the interaction with staff was no less important. For the interviewees, good support from staff meant that the emotional pain of the loss was lessened. Additionally, when the relatives received accurate information it made the reasons for the death understandable. Interviewees perceived that interactions with staff increased their self worth and that there was a potential long term impact on the bereavement process and well being. The supportive relationship also meant that those who needed additional support could be referred on to appropriate services.

Interactions in this study were examined from the perspective of the relatives only and could have been further illuminated with the inclusion of a staff sample. In addition, the methods used in the study are unclear, particularly the analysis which is presented as content analysis. However, important considerations for staff were raised regarding support for bereaved relatives and the long term implications of providing such support. In particular, the link between the circumstances surrounding the death and the course of bereavement appears to be a relevant issue requiring acknowledgement and clarification.

Family members' needs

Milberg et al (2008) explored perceived needs for bereavement follow up of family members' of people who had died in palliative care units. There were 398 deaths during the study period, 377 relatives were included in the questionnaire study, and 248 responses (66%) were received. A need for bereavement follow up was expressed by 46% of family members. The most favoured time was 2-6 weeks after the death and most preferred a home visit. For the 50% of the sample who had been visited 86% evaluated it as good or very good. Qualitative analysis revealed three main themes:

- The person who carries out bereavement follow up should be someone who is willing to listen and someone who knows the patient and the family. The profession of the person who visited was not important.
- Bereavement follow up meant that the bereaved person could share their feelings of guilt, get consolation in their loneliness, and be acknowledged.
- Bereavement follow up should address concerns about what happened before and at the time of the death, present needs, and things that may arise in the future.

The authors concluded that there is a need to identify those relatives who will benefit from follow up so that services can be targeted and that the use of risk assessment tools should be considered. It is however unclear whether follow up facilitates coping and should be offered to all bereaved relatives, or if there are certain groups that may benefit. The quality of this study was good and it successfully explored perceived needs for follow up for this group of bereaved people whose relative died in palliative care. The questionnaire method may

have achieved views from a larger number than an interview study could, however, there may be less richness in the data. Time lag from the death to recruitment may mean that there is recall bias, and changed perceptions of need over time may not be identifiable.

Interventions to address needs

A supportive phone call to grieving family members was evaluated in a study by Kaunonen et al (2000). The purpose was to describe grief four months after the death; describe how the surviving family member perceived the supportive telephone call; compare grief reactions in intervention and control groups. The family member received a phone call a month after the death that allowed discussion of feelings and questions to be answered. It was also an opportunity for the nurse to provide information about grief and about support groups, and it allowed the relationship between nurse and family to be severed. One hundred and eight bereaved relatives in the intervention group were sent the follow up questionnaire, 70 responded (65%). For the control group, 385 relatives were sent the questionnaire, 155 responded (41%). There were significantly more unexpected deaths in the control group, and significantly more individuals in the intervention group perceived any support they had received positively.

All respondents supported continuation of the intervention (98%), 53% knew the nurse who called, and 93% thought the timing of the call was suitable. For 72% the call had an impact on how they perceived the death. The qualitative analysis described family members' experiences of the call as positive and satisfying. Participants appreciated the opportunity for discussion and to have their questions answered. It seemed to bring a natural conclusion to the caring role that had been shared by the family and the nurse. Negative experiences were expressed when relatives had not been called when promised, and calls were short and provoked sad memories. Despair, detachment and disorganisation were more intense in the intervention group and may be due to there being a larger proportion of spouses. A higher mean age of the deceased in the control group could indicate a lower proportion of untimely deaths. However, the intervention group showed significantly better personal growth that may be a result of the experience of losing a parent. The

study indicates that there is a need for a supportive phone call from ward nurses. Further development of grief measurement tools to assess bereavement interventions is also recommended (Kaunonen et al 2000).

2.2.3 Bereavement care in care homes

Only one research study was found in the database searches that specifically referred to care home practice as regards bereavement care, see Table 6 below.

Table 6. Included studies – care home services

Author	Year	Publication	Title	Database	Quality
Katz, J., Sidell, M. & Komaromy, C.	2000	International Journal of Palliative Nursing 6 (6): 274-279	Death in homes: bereavement needs of residents, relatives and staff	Medline	Fair

As discussed in previous sections of the review, the range of services that have been developed for bereavement care in palliative care settings has not been emulated to any great extent in more general healthcare contexts. The study reported here was designed to investigate the case for applying the principles and practices of palliative care bereavement services in care home settings (Katz, Sidell and Komaromy 2000). It was a qualitative study that included questionnaire, interview and observational methods. One hundred home managers were randomly selected from 412 to be invited to take part in an interview. Interviews collected detailed data on management of the last three residents who died, approaches to caring for dying residents, and effects of death on care staff and other residents. Twelve of the homes were then selected as case studies. Researchers spent a month at each home observing and conducting interviews with staff, other professionals (Drs, community nurses, palliative care teams, physiotherapists), residents and relatives.

Results reported in the paper by Katz, Sidell and Komaromy (2000) focused on bereavement care needs of relatives, other residents and home staff. It was found that the majority of employees in care homes have no qualifications or preparation for bereavement and death work, and many are young women

with no personal experience of bereavement. Care workers often see themselves as substitute family for residents and experience distress when they die. Homes have no clear policies or guidelines for bereavement care. Most managers thought they should support staff but how well this was done varied considerably. Their support of bereaved relatives also seemed to end abruptly after the funeral when relatives were no longer viewed as being the home's responsibility. However, managers viewed providing practical and emotional support to the relatives and friends of a resident to be part of their role. A representative of the home usually attended the funeral and follow up contact occurred in some cases, particularly if there was a special event at the home or when the relative visited another resident. This was more common in rural areas, however, some relatives found it painful to stay in touch. Few homes had written guidelines for bereavement care and the level of support generally depended on how well the staff knew family and friends.

A need to provide training for care staff was identified, and care workers believed they needed support though managers had different ideas of the type of support required. Staff were supported to deal with the loss emotionally, but also because prolonged grieving affected their ability to do their job. Lack of counselling skills, lack of time, and being short staffed were barriers to supporting staff. Staff concerns were said to mirror the concerns of residents' when someone dies in the care home (Katz, Sidell and Komaromy 2000).

The study by Katz, Sidell and Komaromy (2000) provides no clear indication of what specifically is provided for bereavement by palliative care services on which care home staff could model their service. There is also no indication of how many managers took part in an interview, or numbers and characteristics of those interviewed in the ethnographic study. In addition, there is no description of the events observed or analysis of the data collected for the observational study. Because the study did give an overview of some of the issues that are considerations when dealing with bereavement in care homes, it was judged to be of fair quality.

2.3 Overview

This review brings together research studies that have examined the experiences of older people when they become bereaved of someone close. It has also amalgamated studies of services or interventions that have been developed to address the needs of the bereaved. The review is now at a stage where some overall messages can be identified:

- research is of mixed quality, and overall there is a lack of studies that could be assessed as good quality;
- there is relatively little research specific to bereavement and older people, and the complexity of grief or the range of situations and circumstances that may be experienced is poorly explored;
- for older people, bereavement commonly affects their physical health; means psychosocial changes including emotional and social loneliness; means changes in relationships with other people and with the self; brings a process of making meaning from the death and continuing the bond with the deceased;
- research into bereavement care provision for older people is poorly developed in general healthcare settings;
- research reviewed indicates a lack of coordination of bereavement care in healthcare settings, poor communication across healthcare settings about the bereaved, and provision that is far from universal.

The literature review and the overall messages provided the direction for development of the two key aims for the empirical research carried out for this thesis project. These were:

- to explore current service provision for bereaved older people who use healthcare services;
- to develop guidelines for the use of healthcare staff that will enable effective case management and communication about bereaved individuals across the sectors.

The aims indicated a distinct two phase study:

- Phase 1. The Interview Study;
- Phase 2. Development of the Guidelines.

In Phase 1, a complete in-depth exploration of current service provision across three practice settings (general practice and community nursing, hospital wards, care homes) was carried out where previously research studies have

concentrated on services in one particular setting. In addition, studies that examine gaps in services and explore how bereavement care could be advanced in practice are absent in the literature. The thoughts and opinions of healthcare staff and bereaved older people were key to developing enhancements that could be practicable. The voice of the bereaved is heard less often in relation to service provision and development, however, in this study their views were key to informing the second phase of the research.

The next chapter of the thesis describes the objectives developed to achieve the aims of the study, and gives full detail of the methodology and methods used to carry out the research. Some markers of quality identified in the studies assessed as 'good' in the literature review were used to inform development of suitable methods.

CHAPTER 3

METHODOLOGY AND METHODS

The methodology and methods developed for the research project are described and evaluated in this chapter. Initially the objectives specifically set for both phases of the research are identified, followed by description and assessment of the philosophical perspectives that underpin the study. The qualitative study design chosen to address the aims and objectives is then described and assessed. This is followed by description of the particular methods used to investigate bereavement care for older people in healthcare services. The methods used to develop the guideline and validate its contents through consultation with stakeholders are then provided, and the chapter concludes with discussion of ethical considerations for the research.

3.1 Objectives

Reviewing the literature and identification of gaps in knowledge regarding bereavement and bereavement care for older people has enabled objectives to be set for meeting the aim of each phase of the study.

Phase 1.

Carry out an interview study to explore:

- current management of recently bereaved older people;
- the interface between primary care and secondary care/independent sector/voluntary sector services regarding bereaved relatives;
- impressions of gaps in the service and the perceived need for enhancement;
- the feasibility of developing guidelines for bereavement care.

Phase 2.

Development of appropriate guidelines for healthcare practitioners:

- use key themes from the interview data, previous research and literature;
- establish feasibility and appropriateness through focus groups with service providers and service users.

The key driver for the research was that its outputs could be disseminated to healthcare practice and the new knowledge utilised (Landry, Amara and Lamari 2001) in the form of guidelines for bereavement care of older people. This may lead to a further phase of engagement with healthcare practitioners following completion of the current research.

3.2 Philosophical direction for the study

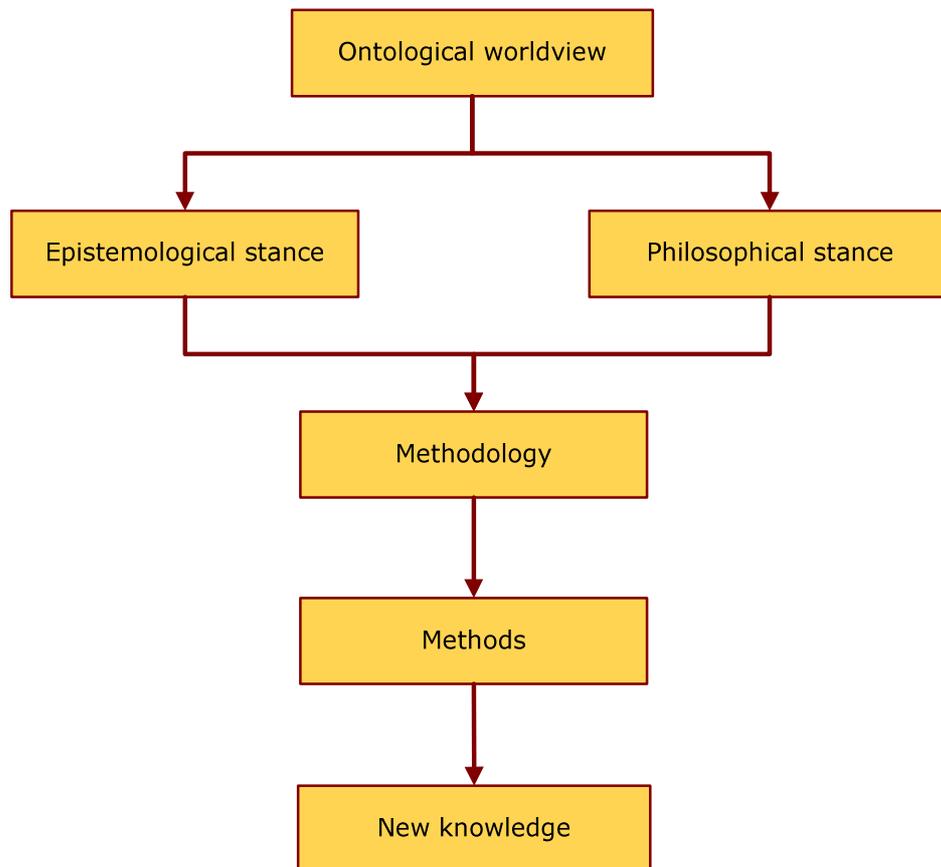
A qualitative design was chosen to address the aims and objectives for the study which would allow exploration of key aspects of bereavement for older people, and bereavement care as delivered by healthcare staff; provide data that, once analysed, informed the development of guidelines for practice; and collect feedback on the guidelines.

Snape and Spencer (2007) indicate that a combination of factors specific to the research design lead to unique approaches to qualitative study. Factors include beliefs about the nature of the social world and what is known about it (ontology), and the nature of knowledge and how it is gained (epistemology), as well as those particular to the study including participants, those whom the study may benefit, the funding body, and the researcher's experiences and beliefs. In addition, particular characteristics of qualitative research emphasise its uniqueness and usefulness in this project:

- it provides in-depth understanding and interpretation of social worlds;
- it uses small purposively selected samples;
- it involves interactive contact between researcher and participant to develop emergent issues;
- it collects extensive and rich data;
- it employs an analytical process that looks for detailed descriptions and creative development of themes that represent social worlds of participants (Snape and Spencer 2007).

To illustrate the development of the research study undertaken basic elements of social research can be described that are related to each other and allow questions to be answered, new knowledge to be gained, or the aims of a study to be achieved (Figure 4 overleaf).

Figure 4. The elements of social research



Validation of methods and methodologies demands exploration of our ontological worldview and epistemological and philosophical stance along with assumptions about the social world and the reality of our situation within it (Crotty 1998). In the present study there was no prescribed order of considering the different elements, and the development of the study did not take place linearly as many texts would suggest it should. The development of the study began with the idea that a qualitative design was the most appropriate means of answering the research questions, engaging healthcare practitioners and bereaved older people, and addressing the gap in the literature as regards bereavement and bereavement care for older people. This then led to the identification of suitable methods, and during the process of their development the understanding of the nature of the proposed research became clearer and it grew into a study that was phenomenologically orientated. There was, therefore, the risk that the data collection techniques chosen were inappropriately attributed within the methodological stance

(Wimpenny and Gass 2000). Practically, the development of the initial processes for the study led to intense reflection on the philosophical underpinnings of the work. This has allowed clearer understanding of important elements that can now be taken to other studies where it may be more likely that the developmental process will occur in a more conventional manner. In addition, to enable development of this project to proceed on a clear timescale determined by a funding application deadline, it was necessary to clarify the intended methods very early in the process. Struggling with the abstract concepts of epistemology and philosophical stance at that point would not have been practical, however enlightening.

Below the realist ontological worldview and interpretivist epistemological stance that validate the choice of qualitative methods for the study are outlined. The constructionist epistemology is then presented to inform the approach taken to phenomenological enquiry. The section ends with an exploration of phenomenological methodology and an argument for using the Duquesne University approach to psychological research (Giorgi 1985) that was developed as a methodology from origins in traditional phenomenological enquiry to explore such topics as pedagogy (van Manen 1990) and nursing (Caelli 2000). The new techniques developed to research human phenomena in a range of fields originally arose in the thinking of scholars at Duquesne School University in the USA during the late 1960s and early 1970s (Giorgi 1985).

3.2.1 The naturalistic ontological worldview

Naturalistic enquiry allows research based on the position that the social world exists independently of conscious thought, but what is known about it and how it is understood depends on interacting with it and forming individual interpretations of meaning (Henwood and Pidgeon 1993). In qualitative research, through a range of interpretations, the social world can be recorded and described in detail. A diverse range of views and perspectives of the world add to the richness of the interpretation of a topic or of experiences of a phenomenon (Snape and Spencer 2007).

3.2.2 Interpretivist philosophical stance

The philosophical stance taken to the study of a topic of interest in the social world provides the context for the developing research process and grounds it in a set of assumptions about the world that inform the choice of methodology (Crotty 1998). The development of this study and understanding of it within the constructionist philosophical tradition indicated a social constructionist and interpretive perspective. This assumes that individuals seek understanding of the world in which they live and work through multiple subjective meanings towards objects or things developed through listening to views formed through interactions (social constructions), historical and cultural norms (Creswell 2007). The influence of the ontological worldview of naturalistic enquiry clearly informs the development of the interpretivist stance. The approach is historically located in the thought of Max Weber (1864-1920) who was concerned with understanding (*verstehen*) in the human sciences and is interested in the human being, his interactions with the world, and the meaning he attaches to experience. However, Weber also searched for causality, a central concern of positivistic science and empirical evidence. More recently, interpretivists have developed the ideas of *verstehen* to a stage where there are distinct differences between methods used in the social sciences and the natural sciences (van Manen 1990). The interpretivist approach taken in this study was phenomenological providing the opportunity to access meaning in bereavement and bereavement care, though in the knowledge that it was possible that important aspects may lie undiscovered.

In this study, bereavement and bereavement care were explored using broad interview questions that allowed participants to construct the meaning. However, interpreting the data through the analysis process inevitably brought a personal perspective to the process. Experience of the phenomena under investigation shapes the way it is understood and may, at times, have informed the development of the project as a whole. To remain subjectively open to the voice of participants in the study and allow them to develop the key themes around bereavement and bereavement care conscious efforts were made to 'bracket,' or keep separate personal perspectives. This meant that the results and outcomes of the study could remain true to the experiences or those who told their stories (Rolls and Relf 2006). However,

this was difficult to achieve in practice as experiences of bereavement in professional and personal capacities, and theoretical knowledge about the topic influenced the development of the study. When interpreting the data it may have been easier to 'bracket' and remain closely with the words of participants, though the risk of contamination remains as researchers interpret experiences already interpreted by participants.

3.2.3 Constructionist epistemological stance

The epistemological stance of a researcher, as indicated above, depends on his or her worldview and how knowledge of the world is obtained or learned. Key elements to consider are: how we know about the world; what information can be considered facts; the nature of objective knowledge and how it can be known; and how we know and learn about the social world. These issues can be explored through analysing the relationship between researcher and researched; examining theories about truth; and considering how knowledge is acquired (Snape and Spencer 2007).

Constructionism is an epistemological position traditionally occupied by qualitative researchers and takes the view that all knowledge is constructed through human beings interacting with the world within a shared social context (Crotty 1998). Constructionists believe that things in the world are devoid of meaning without the engagement of human consciousness that interprets and brings meaning to their existence. The commonly used example of a tree demonstrates that human beings have attributed meaning to make the tree a tree. It is therefore hard to accept that where the existence of a tree is unknown, that that tree is not still a tree. Socially constructed meaning also leads us to attribute different meanings in different settings. The tree has different meaning, for example, in a logging forest, in a shelter belt, or as an ornament in a garden (Crotty 1998). Similarly, different types of death will be attributed with different meanings for the bereaved, for example, sudden or expected, or depending on the age of the deceased. However, bereavement will mean something different for each bereaved relative or friend irrespective of the type of death.

It appears, therefore, that sense can be made of the same reality in different ways. People from different cultures can give different meanings to objects and phenomena, and constructionism posits that there is no 'true' or 'valid' interpretation of a phenomenon. There are interpretations that are more useful than others, for example, they may be liberating, fulfilling, or rewarding (Crotty 1998). Additionally, to make sense of human interpretations or constructions they need to be set in historical and social perspectives. It is not the case that humans encounter objects one by one and make sense of them, rather they belong to a world of meaning. Each person has a system for making sense of the world and for interpreting a set of symbols that allow us to see the world with meaning. We see the world through our culture that leads us to attribute meanings. This gives us shared meaning for social realities developed, maintained and re-enacted through social life (Creswell 2007).

In terms of the current project, bereavement may be a good example that demonstrates this social constructionism and is illustrated by different meanings that are predominant in different cultural groups or across different historical times. For example, bereavement may be experienced differently in Asian communities in the UK when compared to how it is experienced by the majority UK population. It may also be experienced differently in 21st century Britain than it was at the turn of the 20th century. Traditional values, rituals and expected norms within communities influence emotional, physical and social response to loss and mean that healthcare systems must interact with the bereaved in a manner that is culturally sensitive and flexible to need. The methods adopted for this study, in particular interviewing of healthcare providers, were designed to explore the needs of the bereaved in the context of their social lives, and how these considerations are addressed. It was also anticipated that interviewing bereaved older people would reveal, to some extent, the role of culture in the playing out of values and norms around being bereaved. By carrying out the work from a constructionist perspective there was the opportunity to study bereavement and bereavement care in its natural settings to enable interpretation of the meanings people bring to their situation. The methods developed for the project turned the phenomenon of bereavement into a set of materials that represent the social world of

participants including interviews, transcripts, field notes and recordings. The researcher may be described as a 'bricoleur' who fits together pieces of representation to create a sophisticated image of a complex situation (Denzin and Lincoln 2008). Getting closer to the research participants and spending time in the field meant that there was the opportunity for the researcher to obtain some understanding of multiple realities, from which to develop new knowledge (Creswell 2007). Knowledge lies in trying to achieve through interaction a deep understanding and interpretation of the actions, beliefs, and values of the actors involved. This process of piecing together the evidence, though subjective, is inductive in nature and contrasts with a deductive position where theories are accepted or rejected through attempts to refute (Creswell 2007).

3.2.4 Phenomenology

From an early stage of this project it was apparent that the aims and objectives could be addressed using a phenomenological research design. Phenomenology would allow description and interpretation of experiences of being a bereaved older person, and for healthcare staff of providing bereavement care to older people. In particular, it was considered that the identification of multiple subjective experiences would be the way to move towards a more general description and understanding of bereavement and bereavement care (Smith, Flowers and Larkin 2009). However, consideration of the study in terms of taking a phenomenological approach revealed that it did not necessarily fit with the traditional phenomenology described early in the 20th century by the original key phenomenological thinkers, Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). It was clear that the aims for the project could not be reflected through using phenomenology in its true sense. Crotty's (1996) description of the traditional underpinnings of phenomenological thinking and how this was developed through a process of derivation and abstraction to a stage where it could be used to research the meaning of human beings experiences illuminated the reasons for doubting the appropriateness of the chosen methodology. The approach commonly used by nursing researchers was described as a new phenomenology that is conceptually different from traditional phenomenological approaches. Crotty

(1996) criticised its exponents for not recognising this departure and dangerously making claims for authenticity.

The position, however, does not seem so stark when searching for phenomenological application in everyday situations. There may be many questions about the differences between traditional approaches and the new Duquesne University approach to phenomenology in nursing research, but the two may not be unrelated and indeed the modern and practical approach appears to have developed from traditional phenomenology (Caelli 2000). The phenomenological researchers, van Manen (1990) and Moustakas (1994) developed the traditional methodology in a way that enabled reduction of a range of individual experiences to a universal essence of the phenomenon. In particular, they used this technique to explore what phenomena were and how they were experienced. Caelli (2000) explains that this new phenomenology does not consider pre-reflective experiences, but looks for interpretation and perceptions of the experience set within the cultural context of the speaker. Indeed this evolution of phenomenology has drawn on the work of Heidegger to enable its use to be relevant to research in health sciences today. Heidegger explored '*Being*' as the '*Being of an entity*' where the totality of an entity is laid bare by definite parts of the whole subject and using the basic concepts gives the opportunity to form a description of the area for the first time (Heidegger 1962). This was predated by Husserl's phenomenology, developed around the search for the objective reality of '*the things themselves*' through examination of lived experience to access descriptions of phenomena in their original form or their physical reality. His approach did not seek to interpret and report the meaning of the experience, but to see the experience in its raw form as it was lived (Crotty 1998). Husserl's position of going '*back to the things themselves*' was developed to allow the exploration of such things as human emotions. The range of methods designed to qualitatively explore phenomena in human terms allowed the psychological studies taking place to be accepted as '*human science*.' Methods developed were used in a range of different areas and topics, and were tested for rigor, and clear understanding of their application presented. Theoretical justification occurred in later work at the Duquesne University (Giorgi 1985). The focus was on exploration and description of everyday experience through

meaning and interpretation of multiple realities. The aim therefore is to understand the reality of experience to the person as they engage with the phenomenon rather than the more objective reality of the nature of the phenomenon itself (Caelli 2000).

The new style sounds useful though Crotty (1996) has criticised it for not reflecting the constructionist position of Husserl who did not recognise the effect of culture and tradition on phenomena. Objective reality was considered to only be achievable when phenomena were as free as possible from context. However, nursing phenomenologists believe it unrealistic for humans to divorce their experiences from cultural and traditional contexts and seek to understand meanings in the sense of the environment in which they are located (Benner 1994). This reflects Heidegger's position that experiences of phenomena are bound up in context and 'being in the world' clearly influences interpretation (Munhall 1994). Caelli (2000) challenges the position of Crotty (1996) that new phenomenology is subjectivist and opposes the traditional constructivist approach, by saying that the nature of nursing knowledge is not individual but is constructivist and the result of scientific reasoning. She says that most studies attempt to deepen and broaden understandings and believes that phenomenology has developed to enable the approach to be used for research with practical application. In addition, she sees it as providing more thoughtful, reflective and interpreted descriptions of experience than are provided by traditional phenomenology alone (Caelli 2000). This kind of phenomenological approach has the ability to foster understanding of many complex human conditions, for example bereavement, and thus address the central concern of caring for people.

The present study took a phenomenological approach, based on Duquesne University theoretical developments, to enable illumination, description and interpretation of bereavement and bereavement care that is as close to the people and their experiences as possible. The findings could then be practically applied to the development of guidance materials for service enhancement. Currently research that involves healthcare staff and users of services may be considered unethical unless the results are used in terms of knowledge transfer and developing services through informing practice

enhancement (Benner 1994). Knowledge transfer and exchange is seen as an emerging area with potential to develop productive collaborations between researchers and users of research (Kagan et al 2010).

3.3 Methods

The methods used to investigate the phenomena of bereavement in older people and of providing and receiving bereavement care are described below. Assessment is also made of their appropriateness, practical application and ability to achieve the aims for the project.

To guide the implementation of the project an advisory group was formed. Membership was drawn from senior healthcare professionals who would be able to facilitate the research in their areas of employment. Members included a director of nursing from a large teaching hospital; a psychiatrist; a GP; and a manager from a Community Health Partnership (CHP). They were identified by members of the supervisory team, a fellow PhD student who also worked in community nursing services, and through the Grampian Bereavement Research and Interest Group (GBRIG)³. An agreed remit and mode of working was drawn up for the group and an initial meeting took place during December 2007. Subsequent meetings took place six monthly. The GP member of the group was unable to attend the meetings due to pressure of work and a flexible arrangement was made to maintain his input to the work and meet with him separately when his input was specifically required.

The advisory group was particularly helpful at facilitating recruitment by providing names and contact details of fellow professionals in the field. Contacts provided were usually senior people, for example, head nurses who could identify ward or practice staff that may be interested in taking part. The advisory group meetings were also a valuable opportunity to discuss the results of the interview study, the outputs in terms of the guidelines for practice, and dissemination of the study outputs.

³ GBRIG website: <http://www.gbrig.org.uk/>

Phase 1

3.3.1 Population identification, sample selection and participant recruitment

The first aim for the study was to explore current service provision for bereaved older people in healthcare settings. This was to be achieved by collecting data from staff in the areas of interest about their experiences of caring for bereaved older people, and from relatives about being bereaved and their experiences of receiving bereavement support from healthcare staff. The healthcare settings of interest in the study, as outlined in Chapter 1, were non specialist and included general practice and community nursing, hospital wards, and care homes. This is where there is involvement from time to time with the bereaved relatives of patients and residents, many of whom are likely to be older people. The areas also reflect places where deaths are most likely to occur in the UK. The likelihood of dying outside of specialist services is high and indicates that staff working in generalised care settings would have contact with bereaved relatives in the course of their work.

Care home staff were included in the study population because in Scotland, though operating largely in the independent sector, they currently provide long term care to over 31,000 people aged 65 years of age or more (The Scottish Government 2009). People who die in homes therefore are likely to leave bereaved relatives who are also older in years, and whose subsequent bereavement care may be seen as the responsibility of care home staff. There may also have been a case for including social work staff in the study population. However, a meeting with a local authority care manager whose case load included a large proportion of older people indicated that involvement with relatives was minimal. Further exploration of the roles of social work staff was not developed. However, this may have been short sighted and it is appreciated that social work professionals may have a range of roles and contacts with older people, as well as a range of perspectives and experiences of working with bereaved clients.

3.3.2 Study centres and members of staff

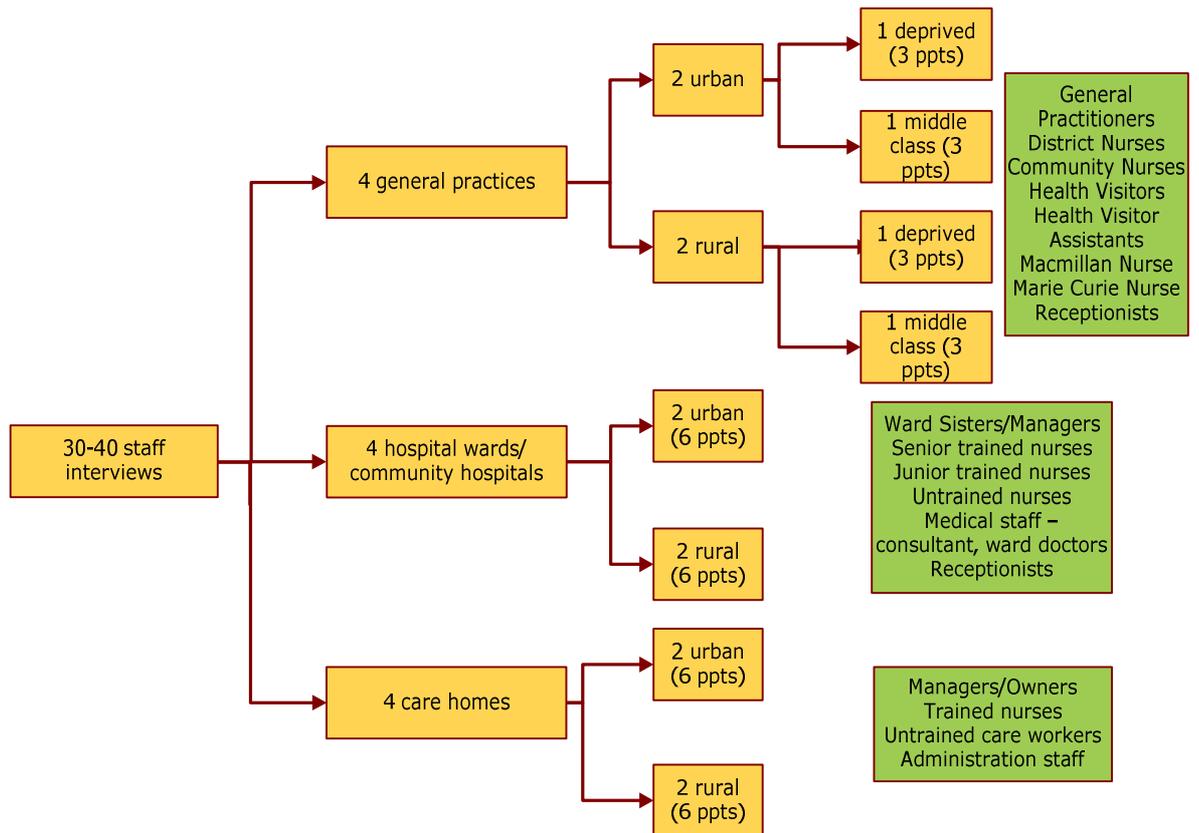
Non-probabilistic sampling strategies are commonly used in small in-depth qualitative research studies for selecting the study sample from the wider

population (Ritchie, Lewis and Elam 2007). Theoretical sampling, as first described by Glaser and Strauss (1967), was the non-probabilistic technique used in this study to recruit participants from the three areas identified based on their role in bereavement care and their area of practice. The aim was to recruit representation from as wide a variety of roles as possible and from different grades, where a grading structure existed. It was also the intention to recruit centres to reflect particular demographic characteristics, for example, urban and rural locations, and deprived and middle class communities. Areas that ranked low in the Scottish Index of Multiple Deprivation (The Scottish Government 2006) were identified and efforts were made to contact general practices and community hospitals in those areas. However, deprivation only appeared in three small areas within the geographical area and consequently only one general practice in a deprived area was recruited. Hospital centres were sampled to include elderly care wards, medical wards, and community hospitals or community hospital wards. In addition, care homes that represented different funding models were approached. These included homes in the private sector, local authority run homes, and voluntary sector funded homes. During the recruitment and interviewing process, the theoretical sampling technique was used to widen the sampling frame to include other staff groups who were identified to have input to the care of bereaved older people, for example, hospital chaplains. This augmented the diversity of the sample and reflected the view that bereavement care is not the responsibility of one single group.

To facilitate recruitment of staff, separate study centres were approached and invited to participate. Figure 5 below is a flow diagram that indicates the proposed numbers to be recruited and the locations for recruitment. Indicated in the green boxes are the staff groups that were known to work with bereaved older people from time to time, and who would be initial recruitment targets.

The possibility of recruitment of a general practice, hospital ward or community hospital, a care home and a bereaved older person within the same geographical location was explored. This would provide a case study of bereavement care within the locality. The recruitment target numbers

Figure 5. Recruitment strategy



indicated are optimal and reflect the amount it was believed to be possible for a single researcher to recruit and interview in the time allocated. Additionally, time for transcribing the data and performing analysis were important considerations. It was also believed that the numbers and roles would represent a sufficient range of views.

The procedure required that a senior member of staff at a study centre was approached and invited to consider whether staff at the practice, hospital ward, community hospital or care home could take part in the research. Members of the project advisory group were instrumental in developing opportunities for recruitment of study centres by providing contact details for key staff known to them whom they believed may be interested in the research. A key person at a study centre was responsible for agreeing that the study could proceed and for facilitation of recruitment of staff in their area. Recruitment procedures undertaken in the study were governed by the Data

Protection Act 1998⁴ meaning that there was no opportunity to obtain lists of names and job titles to individually invite people. In addition, cold calling or sending out unsolicited mail to people asking them to participate was thought to be unlikely to excite much interest or response as well as being unethical. The lead person, who was initially contacted by phone, was commonly a senior ward nurse, a GP, or a care home manager. During the phone call the study was introduced and information provided about what participation of the centre would involve for staff. When the lead person at a centre expressed interest in taking part or in reading more about the study an invitation letter and a detailed information sheet were forwarded by post. The lead person was then expected to discuss the study with staff and to decide whether or not staff at the centre could participate. A period of two to three weeks was negotiated for a follow up phone call to take place.

Following a positive response to the invitation from lead contacts the recruitment of members of staff willing to take part in an interview for the study took place. The lead person at a centre provided the names of three staff members of different grades or roles who had expressed willingness to participate. Invitation letters and detailed study information sheets were then provided for the lead person to distribute to the staff members identified, or posted directly to the staff member. These can be seen in Appendices 2 and 3. The information sheets provided contact details for the researcher and invitees were given the opportunity to request further information and to have questions answered before deciding whether or not to participate. When they had made a decision, invitees responded directly to the researcher by phone, email or by returning the response slip included with the invitation. A positive response allowed direct contact with the participant and an interview date and time was arranged. No further contact was made to anyone who indicated that they did not wish to participate. This procedure worked well and a varied sample of participants was successfully recruited. The most challenging aspect of recruitment was engagement of lead persons at centres, however, following up contacts provided by advisory group members usually led to a person who was willing to facilitate the research. Once lead persons were on

⁴ The Data Protection Act 1998 <http://www.legislation.gov.uk/ukpga/1998/29/contents>

board their input in identifying and approaching staff to take part generally led to recruitment.

As recruitment progressed, attempts were made to purposively select staff in roles that were under-represented in the recruitment profile (Bergum 1989). For example, care home managers were inclined to approach members of staff to take part and did not volunteer themselves. This led to having to ask specifically for a manager to consider taking part as it was felt that their input to bereavement care in a home would be instrumental to the actions and attitudes of staff. In addition, a number of people who had roles in bereavement care, though not a member of staff on a ward, practice or care home, were identified. These included hospital chaplains, care managers from social work departments, counsellors in the voluntary sector, and health visitors. Representatives of these groups were identified, approached and invited to participate, however, recent development of roles in social work and health visiting that will be described in the next chapter meant that recruitment of additional voices yielded mixed success.

3.3.3 Bereaved older people

The inclusion of the views of bereaved older people was a key priority for this project. Development of guidelines that addressed specific experiences of bereavement for older people was seen as a driving force behind the work. Involvement of patients, or service users, or lay people (the terms are used interchangeably) in the planning and development of health care services has previously taken place in many areas including stroke care (Jones et al 2008). More specifically with relevance to this project, the views of bereaved relatives have been included in the development of a framework for bereavement follow up in palliative social work in Northern Ireland (Agnew, Manktelow and Donaghy 2008). In addition, The Scottish Government encourages the inclusion of service user's views in service development and sees it as having key benefits for service users themselves, service providers and commissioners (The Scottish Government 2007).

For this project, the benefits of including a sample of bereaved older people in the study population were in learning in detail about bereaved older people's

experiences of bereavement and bereavement care. Their inclusion also provided the opportunity to explore what was missing or may have helped them in terms of bereavement support. It was also important for the development of bereavement research methods in general to include bereaved relatives in the project to test out recruitment procedures, and comment usefully about the acceptability of taking part in bereavement research. This would inform the development of subsequent research projects in terms of the level of success of the methods, the identification of difficulties encountered and taking forward ideas for improvement.

Bereaved older people were recruited from the population of people who were aged 65 or more, and had been bereaved for at least 6 months and no more than 5 years. They would preferably have been bereaved of a relative or close friend who had died either in hospital, at home or in a care home. In practice, the criteria were feasible for the study, however, there were two relatives recruited who were aged between 61 and 65 years of age. This was due to recruitment taking longer than expected, low numbers, and healthcare staff facilitators being unaware of the relative's age. Participants otherwise spanned the age range up to 93 years. Previous bereavement studies have used a time delay of six months after bereavement as it is thought to be reasonable for allowing the bereaved person to be past the initial weeks when the loss is experienced most acutely (Centre for the Advancement of Health 2003, Schut et al 2001). However, definitions of recovery (Balk 2004) and what represents a reasonable time lapse are difficult to specify and will vary, although some broad time periods (usually six months) have been identified (Beck and Konnert 2007). The request to participate may not appear to be so onerous after this time. In addition, enough time may have passed for bereaved relatives to have experienced different aspects of bereavement, and thought about what it means in their ongoing lives. Including people who have been bereaved up to 5 years will increase the pool of potential participants for this study. However, there may be ethical considerations if people have put the most difficult time in their bereavement behind them and some will have moved on to new relationships. Attempts were also made to recruit a sample with variation by experience, for example, the death was

sudden; after a long illness; of a spouse; of a sibling; of a friend; as well as in time since bereavement and age.

Bereaved older people were recruited to the study via the lead person or a staff interviewee at the study centres. Staff were asked to consider relatives to whom they had provided bereavement care, or had contact with at the time of a relative's death and to approach those that they believed may be able to take part in an interview. They were provided with information about the recruitment criteria. It was anticipated that if each centre identified and approached one or two bereaved older people a sample of twelve could be obtained. This was believed to be large enough to explore a range of experiences. When a relative, who had been approached by a participating member of staff, expressed interest in taking part a letter of invitation and an information sheet was posted to them (Appendices 4 and 5). As with staff, the invitee then indicated their response to the researcher. Bereaved relatives were not contacted again if they did not respond.

The process described above worked well when staff members were willing to consider those known to them whom they felt able to approach. However, recruitment was slow and staff found it difficult to remember relatives of people they had cared for over six months previously. They also found it hard to broach the subject of bereavement with older people whom they had little contact with since their relative's death. To augment the sample other areas for possible recruitment were explored. These included meeting with specialist hospital nurses and community Macmillan nurses and requesting their assistance with recruitment of relatives. Another possible route of recruitment was through an older people's group jointly facilitated by the local authority and Age Concern (now Age UK)⁵. This was an active group of older people who sit on various health and social care strategy development committees and boards as lay members. A visit was made to the group to introduce the study and request that members consider participation. A member of the advisory group for the project who is a GP also agreed to approach relatives

⁵ Age UK <http://www.ageuk.org.uk/>

known to him. In addition, colleagues in GBRIG were asked to consider approaching people known to them in their practice areas.

3.3.4 Data collection

Planning the field work was an extensive phase undertaken during the development of the study. Three data collection methods were used: semi structured interviewing; focus group discussion; and a consultation process.

3.3.5 Phase 1 - Semi structured interviewing

Initially, an interview schedule drawing on methods described by Wengraf (2001) for the development of the biographic-narrative-interpretive method interview was developed for use with healthcare staff. The interview format described was for semi-structured interviewing to take place in three distinct sub-sessions and over two separate meetings. This format was adapted for use in one session as it was anticipated that it may be difficult to recruit healthcare staff into the study for more than one session due to competing work commitments. To begin the interview a single question was drafted to induce narrative and the telling of a story about experiences of caring for bereaved relatives:

- can you begin by telling me about experiences you have had of caring for bereaved older people?

The aim was to allow respondents to talk about their experiences with reassurances and prompts for more information where necessary. This format replicated Wengraf's (2001) first interview session. Wengraf (2001) then described following up with a further session after a period of reflection. The aim was to extract more story from the topics raised. In the current study this principal was relevant, but it was more practical to prompt where necessary for additional information at the time when a topic was raised by the interviewee. The final part of the interview described by Wengraf (2001) raised further questions arising from the topics already discussed. Additionally, to address specifically the aims and objectives for the study, sections were designed to gather thoughts and opinions about:

- communication between services about the bereaved;
- challenges of caring for bereaved older people;
- suitable enhancements to bereavement care for older people.

To further prepare for interviewing, an initial schedule reflecting the contents described above was piloted with three colleagues, all of whom were experienced nurses. The interviews highlighted examples of questions that could be reworded or phrased differently, and indicated where probing for more information was necessary. The pilots also highlighted the need to ask participants directly for their stories of experiences of caring for bereaved older people as interviewees were unlikely to refer to specific examples spontaneously. One interviewee was surprised at how much the interview made her think about bereavement care and to consider possible enhancements. This was a good indication that the interview schedule and process were able to explore new ground with participants and assist them to reflect more deeply (Arthur and Nazroo 2007).

The interview schedule was amended to reflect the outcomes of the first stage of piloting, and the pilot was then extended to two district nurses at the practice of the GP member of the project advisory group. These pilot interviews were scheduled to take place on the same afternoon, one after the other. However, interviewing for an extended period of time gave no opportunity to reflect and amend questions as necessary. This was too intensive and indicated that better practice would be to schedule a break between interviews. The pilot interviews were also used to test the process of gaining informed consent and to clarify the length of time required. The interviews lasted 40 minutes and 36 minutes indicating that this would be required to cover the topics in the schedule. The interviewees gave comprehensive responses though one nurse found it hard to pick out specific people or cases when asked to describe experiences of caring for bereaved relatives. This indicated that more specific questions were required, possibly asking people to describe their most recent experience, or times when interaction with bereaved relatives went well and times when it was more challenging. The interviewees also found it challenging to suggest what could be included in a protocol or guidelines for bereavement care. This was a new area for them to consider and indicated that the line of questioning that enabled interviewees to develop ideas required amendment. The process of reviewing and adjusting continued through the initial set of six interviews with

hospital staff. Indeed, use of the schedule in the field enabled understanding of how it worked in different contexts (Morse 1989).

Further development of the interview schedule took place following attendance at a two day in-depth interviewing course. The value of a more flexible approach using a topic guide as a practical map of the topics and sub topics to be covered was indicated. It was believed that this would be responsive to differences in each interview (Arthur and Nazroo 2007). The revised guide (see Appendix 6), structured around the aims of the project, provided a logical flow through the interview yet was flexible to unexpected topics and topics being addressed in the order they were encountered in the natural flow of the conversation. The opportunity to explore experiences and introduce topics that are important to interviewees was retained. Effective use of the topic guide demanded probing for more information, explanation and examples to obtain depth and richness in the data. Sections of the interview addressed the following topics:

- the research aims and objectives, and the interview process;
- the interviewees background and circumstances;
- current management of bereaved older people in practice;
- thoughts and opinions about bereavement care;
- communication between the services about bereaved relatives;
- enhancement of services for the bereaved.

The initial sections of the guide were designed to take the interviewee into the interview process and allow them to speak about things that were familiar, for example, their background and professional experience. This provided context to the interview that was used in the data analysis and interpretation process. Topics then moved from general subject mapping, for example, communicating with other services about bereaved relatives to more specific ideas about how or why communication takes place. The interview then moved to more in-depth probing for attitudes and feelings about sharing information with others. At the end of the interview the topic guide allowed winding down and moving to more general topics, for example, looking to the future and examining how services could be enhanced. The interview finished off with a general summary of experiences, attitudes or possible developments. The topic guide was adopted for use in all subsequent

interviews and was an aide memoire in the interview situation whilst guiding the interview process in a way that was logical for participants to engage with and was flexible enough to allow for a variety of responses.

Interviewing older people began after approximately half the staff interviews had taken place, and a separate topic guide was developed using the same principles as above. The guide worked well for interviewing staff in the field and it was believed appropriate to use a similar format. The guide developed contained four main sections:

- the research aims and objectives, and the interview process;
- the interviewee's background and personal circumstances;
- the interviewee's experience of bereavement and receiving bereavement care;
- enhancement of services for bereaved older people.

The topic guide for interviewing bereaved older people can be seen in Appendix 7. It was piloted with an older woman whose friend died in hospital. She was approached by a hospital ward sister who had also facilitated recruitment of staff. The pilot indicated that questions seemed to allow the interviewee to tell her story and to elicit relevant information. The interview lasted 29 minutes and she coped well and was unperturbed by any of the points raised. However, it was acknowledged that interviewing a bereaved spouse or close relative may provoke a range of emotional response that this pilot could not reveal.

An information sheet was provided to each participant, whether staff or bereaved relative, prior to the interview taking place and an opportunity to ask questions was provided before signed consent was achieved. In addition, a full explanation about the aims of the study, the format of the interview, and the clauses on the consent form was provided orally prior to the interview taking place. Two consent forms were signed by each participant, one for researcher records and one for the participant to retain. Interviewees were also asked for consent to having their voices recorded as interviews were recorded using a digital recorder.

In many research fields informed consent is routinely gathered to confirm that human participation is non coercive and is based on being fully informed. It could be argued, however, that in qualitative research where the researcher is a tool to the production of useful data, the informed consent process alters the desired neutrality in the power relationship between researcher and research subject (Denzin and Lincoln 2008). The intrusion of the consent procedure on the natural flow of the meeting may hinder or compromise the quality of data collected. An interview with a bereaved older person that took place during this study provided a particularly good example of the consent process intruding on the interaction that was taking place. This is described in more detail in Chapter 4.

Participants in the study were assured at the outset that their participation was kept confidential, and that any data reported would be done so anonymously. Measures taken to protect identities were non disclosure of locations of the study, and allocation of a centre number and participant number to each person. Denzin and Lincoln (2008), however, argue that complete confidentiality and protection of privacy is impossible. They believe that disguised identities are often recognised as researcher perceptions of what is sensitive and participant perceptions differ. In addition, there usually is no clear agreement between the researcher and the researched about specific things that should not be revealed.

Interviews were recorded using a digital recording device with a highly sensitive microphone. Recording the interviews allowed focus to remain on the interviewee, and the interviewer to be alert to opportunities to probe and prompt (Legard, Keegan and Ward 2007). The recordings were transferred to a computer programme for storage and transcription. All interviews were transcribed verbatim allowing re-engagement with the data to identify key points and themes, pick up nuances, and to be self critical of interview technique.

To be an effective interviewer requires being accessible, neutral and interested in the interviewee. These characteristics allowed a process of active interviewing to take place that produced useful knowledge of bereavement

care, and considered the interviewee to be more than a repository of information (Holstein and Gubrium 1998). The development of an initial rapport with the participant, and being clear about the interview process and what was required of the interviewee were steps taken to facilitate a productive relationship. To elicit a true impression of the interviewee's perspective required a neutral stance during the interview. This meant refraining from commenting on interviewees' responses, and bracketing out personal information and opinions (Rolls and Relf 2006). Rather than talking there was a need to listen actively and probe for information appropriately. To maximise potential to remain focused and attentive throughout the interview, attempts were made to adopt a listening posture, maintain eye contact, and to use affirmative non verbal sounds (Wengraf 2001). The sensitive nature of bereavement research meant that there was an awareness that people may find it difficult to speak about certain topics. Throughout interviews it was necessary to remain alert to the emotions expressed by the interviewee and show that their difficulty had been heard and respond reassuringly. Information was not provided about places where further support could be obtained for particular bereavement difficulties that were discussed. It was not believed to be appropriate to do so based on only one short meeting. However, contact details for places where support was available were given in information leaflets for the study. For staff, the NHS occupational health service was identified, and for relatives contact details were provided for Cruse Bereavement Care Scotland⁶. Both services were contacted and permission received.

All interviews for the study took place at healthcare staffs' workplaces or in the interviewees' homes. This meant that there was limited opportunity to rearrange the furniture, and in many cases the rooms provided were set up as consultation rooms and in a way that may not be conducive to interviewing. It would be preferable to sit opposite each other with no table in between, and in some cases sitting across the corner of a table from an interviewee was possible. Other interviews took place in rooms with soft furnishings and were more conducive to open posture and a free flowing discussion. A further

⁶ Cruse Bereavement Care Scotland <http://www.crusescotland.org.uk/>

limitation to the open posture preferred was that there always had to be a place for positioning the recorder.

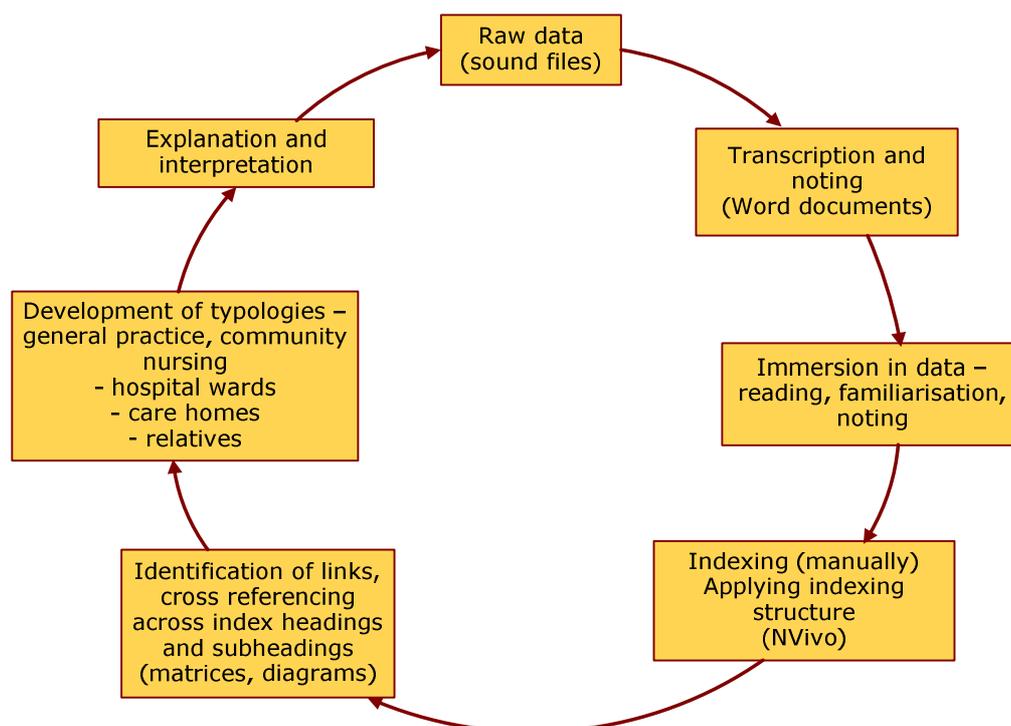
3.3.6 Interview analysis

Interview analysis was a continuous and iterative process beginning during data collection and not finishing until the project was completely written up (Spencer, Ritchie and O'Connor 2007). The approach taken to data analysis in this study was developed in two stages:

- data management where transcription material was indexed, coded and charted to generate key themes and concepts;
- interpretation of the evidence by synthesising parts of the data and forming descriptive and explanatory accounts that mapped the range of topics, concepts and detail in the data.

The aim for the analysis was to capture, portray and explain the social worlds of participants (Coffey and Atkinson 1996) as they engage with bereaved older people, or for older people, in the context of their loss. A dynamic process took place to build up the evidence and key steps are identified in Figure 6.

Figure 6. Data analysis



Analysing the data was not linear and its validity was constantly checked throughout by referring back to the raw data and data transcripts. This ensured that indexing of data in nodes and codes, explanations and interpretations remained close to the context from which they were derived and to the words of participants (Spencer, Ritchie and O'Connor 2007). The separate parts of the process are described and illustrated in detail in the sections that follow. The initial steps of analysis took place simultaneously with continuing to interview participants and at times concepts identified were used to direct new areas of questioning.

3.3.7 Data management

Interview transcription

The data transcripts in the study were vital resources and their detail and accessibility facilitated the whole analysis process (Silverman 1997). Transcription has been identified in the methodological literature as a key step in data analysis and as facilitating the initial interpretation of the interview data (Spencer, Ritchie and O'Connor 2007, Smith, Flowers and Larkin 2009). The process of transcription was undertaken personally and though time consuming, it enabled familiarisation with the data and highlighted points of interest that were regarded as potential concepts or themes that could be included in the analysis. Notes were made continually to track thought processes that led to concepts or identified reasons for extracts being of particular interest. The format of transcriptions was standardised across interviews, for example, all questions asked of interviewees were recorded in bold type and all responses in normal type (Auld et al 2007). This enabled consideration of question and response as a whole and made relocating sections of text easier later in the analysis process.

Listening to the recorded interviews and transcribing verbatim allowed the identification of vocal intonations, pauses and non verbal sounds that conveyed the interviewee's emotions while talking about a specific topic. These were made note of on the transcript to remain visible when rechecking to verify themes. A poignant example occurred when an interviewee sobbed while she spoke about her husband's death. This powerfully illustrated the strong feelings that her husband's loss aroused in her and what it meant in

terms of adapting and coping. However, there was no intention to carry out detailed conversation analysis in this project and use of particular words, lengths of pauses, for example, were not specifically noted. Some interviewees, both healthcare staff and bereaved relatives, used words and phrases from the local dialect which can be extremely expressive and often convey an idea or concept that is difficult to reflect in English. Continuing to transcribe verbatim meant that this expressiveness was maintained and aspects of meaning were revealed rather than concealed (Hill Bailey 2004).

Field notes were also gathered at the time of the interviews and recorded in note form to reflect the situations under which interviews took place. However, throughout the course of interviewing in this study generating field notes that may be useful additions to interview data was challenging. There was no opportunity to observe the interviewee in their natural surroundings, workplace or home environment as in ethnographic research (Smith, Flowers and Larkin 2009). The use of field notes was restricted to that of making note of general impressions of the interview and key themes that arose. In addition the notes were used as reminders of characteristics of the interviewee and the context as regards location, surroundings and time. Field notes were annotated to the interview transcripts and available for referral during the analysis.

After word processing the transcripts the texts were read and reread to become familiar with their contents, immersed in their detail and focused on the participant (Smith, Flowers and Larkin 2009). Some initial hand written notes were made and topics underlined on the transcripts to record initial impressions of things that may be of importance for the analysis. Notes stayed close to the words and context of participants maintaining the intended meaning. Thinking about the content analytically also took place at this time where phrases were questioned and meaning checked out (Smith, Flowers and Larkin 2009).

The data transcribed for this study was voluminous and practical difficulties occurred when attempting to compare themes and ideas across transcripts. A means of handling and organising the data was necessary in order to make

the task more manageable. Spencer, Ritchie and O'Connor (2007, p212) present an '*analytic hierarchy*,' as a practical guide through qualitative data analysis that facilitates the building of a structure of evidence and leads the researcher through the complete process to a valid interpretation. The analytic hierarchy, sometimes referred to as the '*framework approach*,' follows a series of steps that involve different tasks and techniques to move the analysis up the ladder of abstraction (Miles and Huberman 1994). It was used to guide analysis in this study through indexing and coding of transcripts, charting and summarising data, synthesising components and developing explanations. The process was found to be flexible and allowed movement between phases, for example, in the latter stages to go back to the original data to check that interpretations hold true to context. In the early stages of analysis it provided a particularly useful structure for managing the data in terms of coding, charting and identification of emerging themes. In later stages the 'steps' proved to be more challenging and involved a great deal of analytic thought to reach verifiable description, explanation and interpretation.

Identification of index structure, themes and subthemes

Interview transcripts were initially indexed by identifying main themes and subthemes during the process of reading and becoming familiar with the texts. A numbering system was applied to the texts to pinpoint extracts relevant to the theme or subtheme. An example of indexing a transcript can be seen in Appendix 8A. However, the process of indexing was found to be very time consuming and across the interviews there was an unwieldy amount of text that was difficult to view as a whole. To assist with managing data more efficiently the computer assisted qualitative data analysis software (CAQDAS), NVivo 8 (QSR International 2010) was adopted (NVivo 9 has since been launched by QSR International). A range of CAQDAS packages are used by qualitative researchers (Auld et al 2007) and NVivo is one that is widely used in health services research projects and was licensed to the University. This software product can enhance the process of analysis and identification of important areas for exploration (Auld et al 2007). In this study using NVivo helped to speed up the process of indexing and amalgamation of relevant quotes under headings and subheadings.

Transcripts were imported to NVivo and the indexing process continued on from the manual indexing already carried out. In NVivo a main theme is identified as a 'node' and a subtheme as a 'code.' The interviews were coded in groups initially: hospital staff; care home staff; general practice staff; and relatives. Codes were linked to relevant passages in transcripts that are identified by coloured bars and were easily retrievable (Auld et al 2007). An example using a short extract from an interview can be seen in Appendix 8B and parallels can be identified with the manual indexing process already described (Appendix 8A). Codes often were found to overlap each other as indicated by the 'coding density' bar. On working through the analysis it became apparent that all staff interviews could be coded using the same framework of thematic nodes and codes. A separate framework was devised for the interviews with bereaved older people. Throughout the process validity checks took place by reviewing the transcribed data and rearranging nodes and codes until a grouping was achieved that allowed the scope of bereavement care for older to be considered. In addition, to reflect the second aim of the project, the development of bereavement care practice, a particular node was developed to amalgamate suggestions from interviewees for items to include in guidelines for bereavement care.

Charting data

The indexed data was then charted within the node and code framework as a matrix on a series of spreadsheets with shortened extracts or brief notes of relevant data recorded. An example index for 'care at the time of the death' as applied to a small sample of hospital staff interviews is provided in Appendix 8C. This enabled the framework of nodes and codes to be displayed in an accessible format for identification of potential linkages between different parts of the data and between different staff groups, or between staff groups and bereaved relatives.

The nodes and codes were also displayed on spreadsheets without data extracts (see Appendix 8D) and coloured pens were used to identify possible links and connections or similarities. After trying many permutations and testing their veracity by going back to the data, codes that were believed to be related in some way were brought together. Original transcripts were also

revisited and searched to find additional important issues and topics that may not have been identified during coding and these were added to the charts. Charting the data provided a clearer overview of the topic and informed the process of describing and explaining how healthcare staff respond to bereaved relatives, and how relatives themselves experience bereavement. Spencer, Ritchie and O'Connor (2007) see this process of labelling, sorting and synthesising as vital to provide a full picture of what will be included in later analysis and interpretation of the data.

3.3.8 Interpretation of the evidence

Learning how to do qualitative analysis was a personal goal for this project therefore further analysis and interpretation, beyond data management, was carried out manually and in the process of writing this thesis. It was also believed that further training in the use of NVivo would be necessary to be able to use the software effectively in the later stages of analysis. However, the node and code framework continued to be the main resource for checking and rechecking ideas, concepts and potential explanations that occurred throughout the analysis process.

Forming explanations

The data collected in the study came from four distinct groups and using the groups was a natural way in which to classify or categorise concepts and phenomena that emerged. Ritchie, Spencer and O'Connor (2007) refer to this type of classification as developing typologies that can be used to describe regularities in human behaviour relevant to a particular group. Bereavement care for older people as delivered by the three staff groups; general practice and community nursing staff, hospital ward staff and care home staff formed a basis from which to describe processes and begin to explain a range of aspects of bereavement care. In addition, the perspectives of bereaved older people of being bereaved and contacts with healthcare professionals around the time provided a further typology. The accounts of the bereaved were used to endorse or refute explanations developed for healthcare staffs' behaviours. For example, healthcare staff explained that bereavement care, and particularly follow up, was based on having an established relationship with a patient's relatives. However, relatives in the study gave no indication that this

kind of care was universal even though there had been long periods of illness and contacts with healthcare staff before the death.

Explanatory accounts arose from the identification of the multiple dimensions of a node (Appendix 8D), and the range of aspects that were apparent across codes relevant to that node (Appendix 8C). In addition, linkages between dimensions or sets of dimensions were identified. Diagrammatic representation was a method used to great effect in this study to trace and explain links and relationships between nodes and codes. These were used to develop themes and illustrate processes and provide explanation for the theme. Examples can be seen in Chapter 5, the results chapter of the thesis (pages 132, 148, 143, 150, 169, 172). The diagrams developed illustrate various aspects of bereavement care that contain complex explanatory elements and identify linkages between concepts and ideas contained in the data. Diagrams have frequently been used to illustrate themes in qualitative research, for example, Rose and Mackenzie (2010) in a study of clinical decision making of occupational therapists in pressurised roles to depict the role and main influences. Miles and Huberman (1994) describe diagrammatic representation as a means of identifying relationships between concepts and displaying recurring patterns and themes by pulling together pieces of data. However, though regularities are recognised in structures devised they should remain flexible to accommodate items that vary from the usual pattern.

Explanations for links emerged through participants explicitly providing their own explanation, or the development of implicit explanation in the process of writing up the results chapter. Again at this stage the process of checking across data synthesised earlier in the analysis or in the transcripts was carried out to verify that the links held true. In Table 7 overleaf the example of the relationship between healthcare staff and a patient's relative is used to demonstrate this process. Links also occurred between typologies, for example, for hospital and care home staff there was a link identified between the nature of the care establishment and closing the relationship between healthcare staff and relatives very soon after the death of the patient. However, for community staff the relationship may be carried on for longer and the closing down of the relationship is experienced differently. Across the

Table 7. Explanatory framework for a theme

Theme	Dimensions	Links	Implicit/explicit explanation
Relationship – staff/family	Facilitates preparation for the death, support at time of death, follow up	Established relationship leads to preparation, care at time of death, follow up	Explicit (staff)
	Determines who best person to support may be	Period caring for dying patient allows relationship to develop	Implicit
	Facilitates identification of needs post bereavement	Bereavement follow up only helpful if supporter known to relative	Explicit (staff, relatives)
	Some relationships staff/relatives are poorly established (sudden death, inconsistent contacts & poor communication pre bereavement)	Poorly established relationship means bereavement care is inconsistent	Implicit
	Ending relationship happens soon after death (hospital/care home)	The death ends the supportive relationship	Implicit
	Staff and relatives have a bond i.e. care home	Bond doesn't necessarily lead to support in bereavement	Implicit
	Emotional impact on staff	After the death, need to return to other patients/ residents	Implicit
		Ritualistic behaviour to express/hide feelings	Implicit

main themes developed, patterns of association were examined closely and explanations offered for why they may occur and why they may not in certain situations.

In addition to the formal procedures described above that led to explanatory accounts of the data, much thought and careful consideration went into concepts and ideas that emerged throughout the time of analysis. The themes that were developed as overarching brought together the results of the formal

processes and the broad range of associations and explanations that arose spontaneously and could be verified by the transcribed data. The major explanatory themes relevant to bereavement care for older people are presented in full in Chapter 5 of this thesis and extracts of data are used in support of explanations. The explanatory accounts were then developed to support and inform recommendations presented in the guidelines for practice (see Chapter 6).

3.3.9 Phenomenological analysis

Two types of data were collected through the interviews, that which could be analysed thematically and that which was phenomenological in nature and recounted particular experiences in story telling format. Concurrent with the process of thematic analysis described above, analysis of phenomenological data collected in the staff interviews was carried out. This data reflected 'stories' of experiences staff interviewees described of caring for, and interacting with particular bereaved relatives. Stories varied in length and the amount of detail provided depended on how recently the incident took place and the amount of engagement the staff member had with the bereaved person concerned. Examples can be seen in Chapter 5 (boxes 1-4) where 'stories' were used to illustrate and explain particular points made within the main themes.

Coding the 'stories' in NVivo was attempted but was found to be unhelpful and the codes became twice removed from their context and their essence was lost. A procedure described by (Smith, Flowers and Larkin 2009), of the Duquesne University psychological research team, was identified and used to manage the phenomenological data. Working with the data in this way provided some understanding of the situations described from the point of view of participants, and from which reflection on the meanings of experiences could take place. A four step process was applied to each example of a participant's experience of bereavement care (an example is provided in Appendix 8E):

- Reading and becoming familiar with the data as described previously, but also involving engagement to an extent that the experiences of the story teller were understood by the reader as if they were their own.

- Identification of meaning units in the text, where phrases and words were identified as the parts that retain and describe the meaning of the experience. Meaning units relevant to different aspects of the same topic within the data were highlighted in different colours.
- Judgments were made about the meaning units in terms of their relevance to revealing the phenomenon of caring for bereaved older people. Redundant statements that did not assist in illuminating bereavement care were discarded.
- The remaining meaning units were reordered and used to re-describe the whole experience staying as close as possible to the words and phrases used by interviewees and being explicit about what each reveals about bereavement care.

The individual descriptions were examined and intense reflection on meaning took place to identify factors that were important and may complement or supplement the nodes and codes developed for non phenomenological data. These were added to the indexing structures and coding matrices developed in the thematic analysis described in sections 3.3.6 – 3.3.8. The main advantage of the Wertz (1985) method was that it allowed interaction with the data in a way that enabled the researcher to become immersed in the experiences and reflection to take place on the meaning for the interviewee. The parts of the experiences extracted for inclusion in the later analysis processes may not be free from personal judgement of importance. However, as Wertz (1985) argues the researcher's presence deeply implies the identification of key themes relevant to experiences described in the data.

Stories were harder to define in transcripts of interviews with bereaved older people than in staff interviews. This was because most of the narrative was considered to constitute phenomenological story telling, or description of experiences. Carrying out the Wertz (1985) stepwise process outlined above was found to be unmanageable due to the large amount of data in the transcripts (average 7,000 words each) and time constraints for the research schedule. Therefore, the framework approach of Spencer, Ritchie and O'Connor (2007) was applied and found to be the most efficient way to manage the process, identify nodes, codes and themes, and make

interpretation of the meaning of experiences of bereavement and bereavement care.

The process of analysing the interview data collected in the study was multifaceted, challenging throughout, and at times frustrating. Spencer, Ritchie and O'Connor (2007) describe qualitative analysis as requiring a mix of systematic searching and creativity. The processes described above make this a fairly accurate summary of the experience of data analysis in this study. The process was never a clear linear method but more a series of trying out and testing a number of methods that were described in qualitative research text books, in the literature, at training events and as discussed with colleagues. Denzin and Lincoln (2008) describe qualitative researchers developing and using the strategies they have at hand, or indeed putting together new tools and techniques to facilitate piecing the story together. Some techniques tried in this study led successfully to a further stage of analysis while others were unable to further illuminate bereavement care and the experiences of bereaved older people. Four key themes were developed in the course of analysis and are presented in Chapter 5 of this thesis. They incorporate description, interpretation and explanation of the social worlds of participants as they care for bereaved older people, or experience being bereaved and receiving bereavement care. They also provide a bridge between the data and the development of suitable guidelines for bereavement care.

Phase 2

3.4 Development of the guidelines

Analysis of the interview data fed into the development and validation of a draft version of practice guidelines to inform the care of bereaved older people in healthcare services. This reflects the second aim of the project. The guidelines were designed to assist healthcare practitioners in the areas of general practice and community nursing, hospital wards, and care homes to make appropriate decisions about care provided to bereaved older people (Bowker et al 2008). Overall it was determined that the guidance could inform healthcare staffs activities to provide care that was sensitive to needs and

circumstances and could improve older people's abilities to cope with their losses.

The themes developed through analysing qualitative interview data as presented in Chapters 5 were used to inform the development of a draft version of the bereavement care guidelines. This was supplemented with suggestions that were given by participants for items that could be included in the guidelines. Examples of inclusion criteria were also found in the bereavement literature and existing guidelines, for example, the DOH guidelines 'When a Patient Dies' (DOH 2005). Some items included were extracted from the data and also located in the literature, for example, noting the bereavement in the GPs records for the bereaved older person. The initial steps in development of the guidelines used a timeline describing experiences of bereavement and bereavement care developed through the data to identify particular elements that could be addressed by staff who cared for bereaved older people (see Chapter 6). An initial draft was structured by the timeline and sections reflect pre bereavement preparation, care at the time of the death, and care after bereavement.

A second draft of the guidelines was made with the intention of developing a document that was formatted in a way that was familiar to healthcare staff who had taken part in interviews and would be consulted on its suitability and feasibility in practice. Reference was made to the layout of NHS QIS guidelines (NHS QIS 2010); Scottish Intercollegiate Guidelines Network (SIGN) guidelines (SIGN 2009); and Johanna Briggs Institute (JBI) evidence based practice series (JBI 2003). Ideas for improving the layout and formatting were developed within the second draft. In addition to a full version of the guidelines it was believed that a shortened version would be useful for staff to use as a quick reference point where they can see at a glance the key recommendations (Bowker et al 2008). This was developed from the drafted version of the full guidelines and involved summarising the material into small brochure format. When the draft guidelines were finalised they were printed and bound in preparation for sending out to study participants and inviting their feedback on suitability for use in practice.

3.4.1 Phase 2 - Data collection

Validation of the outputs of the project, the bereavement care guidelines, was carried out through focus group discussion with staff participants. Copies of the draft guidelines were sent out with invitations to attend a group meeting to provide feedback on contents, layout, suitability and feasibility for use in practice. A series of meetings were arranged to facilitate participant feedback. Participants who were located in close proximity to the university were sent copies of the draft guidelines and invited to attend one of three focus group meetings. Different dates and times were provided to give maximum choice and to take account of shift patterns. Participants were asked to return a reply slip to the researcher indicating which group they would be willing to attend. Those who practiced in rural areas were contacted by phone to introduce the guidelines and discuss the best way of obtaining feedback. The guidelines were posted out and after 2-3 weeks, giving enough time for participants to read them, they were contacted by phone to arrange feedback meetings at the participating centres. Key contacts at centres were asked to share the documents with staff not already participating in the research in their place of work and to also invite them to provide feedback. Inclusion of those who had not taken part in the study previously would provide a wider range of views.

To avoid the inclusion of bereaved older people in the study being viewed as tokenism (Beresford 2002), those who had participated in an interview were also included in the later stage of the project to evaluate the guidelines. Their inclusion would enable discussion of whether or not the guidelines would address the emotional, physical and social support needs of bereaved older people. They were sent copies of the guidelines and invited to give their feedback at a focus group meeting that was scheduled to take place separately from staff groups. Those who lived close to the university were given a choice of dates and times and asked to indicate those that they could attend. When all replies were received the most popular date and time would be identified. Participating older people who lived in rural locations were contacted by letter and asked if they would be willing to read the guidelines and provide feedback. They were asked to contact the researcher to indicate

willingness to take part. The guidelines were then sent to participants and arrangements made for a follow up meeting.

This part of the project was not about the generation of new data from individuals, but designed to focus people on the guidelines and their usefulness in practice. Separate topic guides were developed for staff focus groups and the group of bereaved older people (Appendices 9 and 10). Topics covered were thoughts and opinions about the usefulness of the proposed guidelines; whether they meet the needs of staff and bereaved older people; how they could be used in practice; the anticipated benefits for staff and bereaved older people; and to gauge willingness to use the guidelines in practice. Focus group discussions were scheduled to last approximately one hour and were digitally recorded. Recordings of focus group discussions were replayed and notes taken of the key points that were raised. The guidelines were further developed in light of what was said in the group discussions with the aim of producing a version that is useable in practice and facilitates enhanced care for bereaved older people within healthcare services.

3.4.2 Consultation on the guidelines

As well as holding focus groups with staff from participating centres there was engagement with other groups who have an interest in care of bereaved older people. This included members of the project advisory group, hospital based specialist cancer nurses, a multi-disciplinary bereavement interest group (GBRIG), members of the bereavement and loss forum of CHAIN (Contact, Help And Information Networks)⁷. Other contacts who gave feedback were located in palliative care services, clinical governance, the School of Nursing and Midwifery of the university in which the researcher was based, and the National Bereavement Framework Group⁸. Feedback was obtained by providing copies of the draft guidelines and inviting comments at a meeting, by email or by phone. To consult members of the CHAIN group who are located across the UK, the documents were placed on the university website along with a web based questionnaire. The questionnaire can be seen in

⁷ CHAIN website: <http://chain.ulcc.ac.uk/chain/index.html>

⁸ Bereavement Care in Scotland website:
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/bereavement>

Appendix 11. It was piloted with colleagues in the faculty research office and the School of Nursing and Midwifery at the university before circulation to CHAIN. Contact was made with the group by email via the CHAIN co-ordinator who sent out a request for participation along with the link to the website.

Feedback on the consultation was recorded on a computer spreadsheet application. The decision making process that took place while considering amendments to the draft documents, and actual amendments that were made were also recorded on the spreadsheet. An extract is shown in Appendix 12. Finalised versions were completed and were made available on the university website where interested parties could be directed.

A key consideration in the development of appropriate research methods for use in this study was to ensure that the rights of participants in the study were protected and their well being was safeguarded at all times. The final section of this chapter describes in detail the application of ethical principles in the study.

3.5 Ethical considerations

Ethical considerations for the study were framed around the key principles of the Declaration of Helsinki set by the World Medical Association and adopted world wide in 1964 as a set of ethical principles for the medical community regarding human experimentation (last amendment in 2008) (World Medical Association 2008). There are ethical implications at every stage of the research process, even as regards whether or not to research a topic (Parahoo 1997). RECs base their judgements of the ethicality of proposals that are scrutinised on the basis of utilitarianism and deontology (Biggs 2010). Utilitarianism examines the consequences of actions to determine whether they are morally right, or correct, allowing the net benefit of the research to be identified. Deontological theory bases judgement on a duty based perspective where certain actions are either right or wrong and the consequences are irrelevant. For example, healthcare research often involves acceptance of a certain level of risk in order to generate useful data that may be beneficial for others. In the case of bereavement research this may be in

terms of emotional upset. However, this in itself is not seen as unethical as long as the participants' rights are upheld and they have the ability, for example, to give or withhold consent (Biggs 2010).

Further explanation is given below of the ethical concerns for this study in terms of making morally right decisions, and giving attention to the rights of participants that arose during development of the methods outlined above. Procedures were developed to comply with the University Research Governance Policy, the University Research Ethics Policy, and were subject to ethical review from the local NHS REC and the NHS Research and Development (R&D) Office. The comprehensive guidance for researchers provided by The National Research Ethics Service for the NHS (2009) was used to inform ethical decision making. Approval for the project to proceed was achieved from the three bodies identified.

Bereaved older people may be viewed as a vulnerable group for recruitment to a research study (Stroebe, Stroebe and Schut 2003), therefore, it was important to ensure that their recruitment and participation in this study was fully compliant with ethical principles. Key principles of ethical research commonly identified in research texts, and vital to the conduct of this study are that:

- research should be of benefit to participants or to the wider society, and should cause no harm;
- participants are fairly treated;
- autonomy, rights, dignity and well being of participants are protected;
- confidentiality is respected (Parahoo 1997, Biggs 2010, Stroebe, Stroebe and Schut 2003, Hammick 1996).

Whiting and Vickers (2010) identified a useful tool to frame the development of ethical research procedures in their study with palliative care patients. The tool, entitled the 'Research Ethics Wheel,' was originally described by Hammick (1996) and has four key aspects: principles of research using people; duties of the researcher; nature of the outcome of the research; and practicalities of the research process. These were used to guide development of the methods for the study, however, the aspect entitled 'nature of the

research outcome' was felt to be repetitive of other aspects. For this particular study, it is subsumed in the other three aspects.

3.5.1 Principles of research with people

Relevant research examines a question or topic in a way that will reveal new insight, and in healthcare research investigation of practice related topics is seen as legitimately informative (Parahoo 1997). In this study, reviewing the literature identified the gap in knowledge as regards what is done for bereaved older people in the healthcare settings of interest in the study. New knowledge was to be gained through the study, and enhancements of bereavement care identified from the data collected. Phenomenological methodology that used in-depth interviewing and group discussions as the key methods of data collection provided a scientific basis for the study that demonstrated congruence between the study aims and procedures.

Ethical principles state that all participants in a study must be treated fairly and equitably. In this study purposive sampling of staff participants and bereaved older people took place via lead persons at study centres. To obtain a range of perspectives healthcare participants were selected based on their roles, grades and location of practice. Minimal selection criteria were determined for recruitment of bereaved older people, however, it was determined that participants should be 65 years of age or more, and bereaved between 6 months and 5 years. Beck and Konnert (2007) found in their study of bereaved relatives' opinions about participation in research that it would be appropriate for researchers to make contact in the first two years of bereavement. In addition, working with healthcare staff in their gate keeping role to identify suitable participants was essential to the success of this study. This meant that opportunity to participate was not given equally. However, it was not believed to be unethical as it minimised bias and ensured a range of demographic characteristics and experiences were represented in data collected (Ritchie, Lewis and Elam 2007). In the second phase of the study, all participants were given equal opportunity to provide feedback on the guidelines, and arrangements were developed to facilitate the process.

Provision of adequate information about the study and what was required of participants ensured individuals could autonomously decide whether or not to take part. This is closely linked with consenting procedures, explained in more detail in the next section. Bereavement is not a topic that everyone will feel comfortable to discuss with a researcher, and being clear that participation was entirely voluntary was a key aim of information giving in the study. The information provided, however, did not give detail about exactly what would be asked in an interview, potentially meaning that fully informed consent was not achieved (Allbutt and Masters 2010). In addition, qualitative research interviewing is dynamic in nature and questioning may depend on what comes up in the interview. Changes may also require to be made to topic guides reflecting issues that have arisen in data collected (Arthur and Nazroo 2007). The REC, however, recognised this as part of the qualitative research process and supported the development of the work in this way.

It was also important that participants did not feel coerced into taking part, and no financial or other inducement was given other than travelling expenses to group discussions. However, access to bereaved older people was via known healthcare staff with whom there may have been an existing relationship. It may be that relatives were influenced by a respected person, for example, a GP asking them to take part in the study. It was, however, a key point for the REC that access was through someone known who would introduce the researcher and the study.

3.5.2 Duties of the researcher

Veracity, or truthfulness, and consent are linked with enabling people to act autonomously regarding participation (Hammick 1996). In this study all that was required of participants was stated on information leaflets and in verbal communication prior to taking consent. Opportunities were provided for people to ask questions allowing the weighing up of risks and benefits (Hammick 1996). It was explained to bereaved relatives that they themselves may not benefit directly from taking part in the research. In common with many research studies, improvements in care or treatment outcomes for others was acceptable for participants in terms of benefits (Whiting and Vickers 2010). Staff taking part in the study may, however, find benefit from

participation if the guidelines produced could support and enhance their practice.

Developing a trusting rapport between researcher and participant was key to collecting relevant and detailed data (Whiting and Vickers 2010), and in this study the informed consent process was key. Potential participants were given information sheets that contained full details about what taking part in the study would mean for them, and the risks and benefits of participation. Opportunities were also provided to have questions answered and data collection procedures explained. Autonomous decision making was facilitated with opportunities built in for refusal to take part, and there was openness from the researcher about the participants' ability to withdraw at any time during the study (Stroebe, Stroebe and Schut 2003). Additional reassurance about storing data confidentially, and anonymity in published and unpublished outputs were given to reinforce the participant's rights and ensure confidence in the research and the researcher. Procedures were built in for storing and reporting the research data, and these were also detailed in information about the study.

In qualitative research the types of risks encountered may include anxiety and distress; exploitation; misrepresentation; and opportunity cost (Richards and Schwartz 2002). In terms of the interview study, the risk of distress was high when discussing bereavement with relatives whose loss may have been fairly recent, of someone particularly close, or in a range of different circumstances. Distress, however, may not be a reason for not furthering knowledge by carrying out investigation in the topic area, or not participating. During data collection participants were informed that they could take breaks during interviews, and encouraged to do so where necessary. Additionally, information leaflets contained contact details for the local NHS counselling service for staff, and a voluntary sector bereavement service for relatives (Stroebe, Stroebe and Schut 2003). Permission was received from both services prior to inclusion in participant information sheets. Due to the short contact time and limited knowledge of the bereaved older people taking part in the research, it was not believed to be appropriate to verbally reinforce information about counselling services at the time of the interview.

Exploitation of research participants may occur when there is power imbalance between the researcher and the researched (Richards and Schwartz 2002). In this study, there may have been temptation for both or either parties to turn the encounter into a therapeutic session. However, this was actively avoided by use of the interview schedule and emphasising the aims of the research. Loneliness was, however, a major factor for half the bereaved older people taking part. The presence of another person may have meant that for them the session was more about social interaction than research. Social interaction in a research setting is, however, important for building the relationship between both parties. Attempts were made to achieve a balance by taking part in general conversation and gradually leading the participant into the research topics.

In qualitative research there is also the risk of misinterpreting participants' words. A researcher's interpretation is only how they perceive the situation and the participant, and may even be based on preconceived ideas (Richards and Schwartz 2002). During data analysis it was, therefore, a key concern to concentrate on the data and attempt to bracket out personal judgements. Themes reported in this thesis are supported with raw data to demonstrate their origination in the words of participants. However, this bracketing process was challenging and there may be no way of knowing whether it was fully achieved.

The main risk for healthcare staff, apart from the upsetting nature of the research topic, was the opportunity cost of taking part in the research. Most, at some point in contacts with the researcher, identified pressure of work as a difficulty. Taking part in the research meant taking time out of their usual working day. Pressures were minimised by keeping the interview time within the scheduled 45 minutes, carrying out the interview in one session, and allowing participants to be interviewed at their place of work. Re-engagement of participants for the second phase of the study was identified as a potential difficulty. Procedures outlined above, including provision of a range of meeting times, were developed to maximise opportunities to participate.

Duties of the researcher during the project also include self care. It was anticipated that there was potential for emotional distress when hearing about difficult experiences of participants. Discussion of such feelings was always available within the supervisory team, and in addition, a further colleague at the university was identified who would be able to provide support.

3.5.3 Practicalities of the research process

The research carried out needed to be justified in terms of the external environment in which it took place and the codes and laws determining research practice. The University Research Governance Policy was used as the main guide to ethical practice. This supports meeting requirements of funding bodies; managing risk; improving the quality of research; protection of the researcher; and safeguarding of the public. However, when carrying out data collection in the healthcare settings relevant local policies drove the scope of the work. For example, an honorary NHS contract was granted for the duration of the study to enable access to healthcare staff, and securing their participation. In addition, the Advisory Group for the project met at six monthly intervals during the project and reviewed progress. The importance of the topic for research, scientific rigor and ethical application of methods for the study were reviewed by the funding body at the time of application. Following securing of funding it was reviewed by the NHS REC and NHS R&D. This meant that independent consideration of the study had taken place, providing assurance to the researcher and research participants that procedures were appropriate and safe.

The ability of the researcher to conduct the research is also a key consideration for ethical research. The researcher was able to demonstrate to relevant bodies suitable training that included degree and post graduate qualifications. The fellowship award that enabled the research to proceed also provided a substantial amount of funding for training and personal development. A number of courses attended were on the specific research methods to be used in the study, for example, in-depth interviewing.

Planning for dissemination of results of the research was also an important component of reviewing the research in terms of its rigor. Publication in peer

reviewed journals will facilitate furthering of knowledge of the topic (Whiting and Vickers 2010), and may encourage enhancement of practice in bereavement care. Conference presentations took place throughout the study to communicate findings and to ensure that the research was progressing in a way that was beneficial for bereaved older people and for healthcare practice. For example, examination of participant recruitment methods took place in a poster presentation at a primary care conference. The guidelines for bereavement care and dissemination to practice areas is key to enhancement of support available for bereaved older people.

Sharing the results and outputs of research with participants may be desirable and ethically good practice. In the second phase of the study draft versions of the guidelines were circulated to all participants and feedback was invited. Those who requested updated copies were directed to electronic versions on the University website. For bereaved older people, poor response to Phase 2 of the study and the withdrawal of a participant indicated that engagement with the material may be emotionally difficult. No further contacts were made regarding the results of the study. Appreciation of bereaved older people's efforts to take part in the study was acknowledged in thank you letters, and contact information for the researcher was provided.

Research of any kind has a number of ethical issues to understand and the development of methods and procedures that protect the rights, dignity and well being of participants is challenging (Stroebe, Stroebe and Schut 2003). The discussion above has outlined particular issues in bereavement research relevant to inclusion of healthcare staff and bereaved older people, and has identified a high level of complexity in decision making. The next chapter explores the outcomes of decisions in terms of the success of sampling and recruitment procedures, and experiences of data collection in the study. In particular, analysis will be made of the adequacy of the research sample, the ability to capture the phenomena through the interview study, and assessment of the data analysis and interpretation process.

CHAPTER 4

RECRUITMENT AND DATA COLLECTION

This chapter of the thesis highlights experiences of recruitment and data collection encountered in the study. It is included to reflect discussions that took place in the research team about particular aspects of the research. The many challenges that occurred during the project are the main focus. There was also a need for the results chapter (Chapter 5) to be clearly focused on the findings without also dealing with the issues raised here. Initially, recruitment numbers, facilitators and barriers to recruitment are discussed. Reasons for difficulties in, for example, engaging with people who would potentially facilitate the study and identify bereaved older people, are considered. Later in the chapter pragmatic issues related to the field work are described, with critical reflection on individual elements and analysis of the effectiveness of skills and techniques adopted. Carrying out the field work for the study revealed a number of factors that are considerations for research in sensitive topic areas, for example, the risk of people becoming emotionally upset. However, the value of engaging with informants who have had difficult experiences is highlighted.

4.1 Participant recruitment

Successful recruitment procedures are crucial to the conduct of studies in healthcare research. However, selection and sampling of participants is often challenging and in some cases leads to significant delays in project timetables with substantially increased workload, costs, risk of study termination and reduced generalisability (Ross et al 1999, Goodyear-Smith et al 2009, Miller, McKeever and Coyte 2003). Consequences of recruitment difficulties of this type are well described in clinical trials, but in qualitative research relevant issues are less well explored. Qualitative studies commonly use theoretical, or criterion, sampling techniques particularly where methods such as in depth interviewing are employed to explore sensitive issues (Gledhill, Abbey and Schweitzer 2008). Participants are selected on the basis of known characteristics or experiences that will enable exploration of the main themes (Ritchie, Lewis and Elam 2007), and inclusion evolves as the study progresses (MacDougall and Fudge 2001).

Texts often give the impression that recruitment is a clear linear process, however, in reality it is fraught with difficulties and often becomes delayed. MacDougall and Fudge (2001) identified particular problems with recruiting participants for interviews and focus groups on a sensitive research topic when 'gatekeepers' are involved, invitations were impersonal, timing was inappropriate, incentives were not offered, and recruitment did not build on existing relationships. A systematic review by Miller, McKeever and Coyte (2003) of recruitment issues in healthcare research across a range of designs additionally found that the experience of the recruiter and their relationship with participants were important factors. Flexibility and the availability of a range of recruitment strategies were necessary. Factors that influence participation were altruism and provision of incentives, while barriers to older people taking part in research were fear of strangers, others making the decision, poor health, and caring responsibilities.

In the current study separate recruitment procedures were developed for healthcare staff and for bereaved relatives. Recruitment and interviewing took place simultaneously and began in early 2008 and was completed during May 2009. The agreed recruitment procedure as outlined in the methods section was:

- telephone contact with a key person at a centre who may facilitate recruitment in their area, for example, GPs, senior hospital nurses, care home managers;
- information about the study provided;
- contacts asked to discuss the research with staff;
- follow up phone call to find out if staff would be able to take part;
- contacts asked to identify staff with a variety of roles who were willing to take part;
- contacts asked to identify and make an initial approach to bereaved older people who may be able to take part;
- invitation letters and information sheets sent to potential participants;
- willingness to participate indicated by phone, email, or returning a tear off slip;

- interview appointments arranged.

The recruitment strategy for the study was based on the principal that identification of a lead person in a healthcare setting is helpful and leads to communication about the research with other staff (Shelton et al 2002). The key person approached and invited to take part in this study was expected to read the study information, speak to staff about participation, and support recruitment.

Theoretical sampling led to staff participants with a variety of nursing and medical roles in the settings identified as being key to providing bereavement care to older people who have suffered a significant loss. In addition, discussion with interviewees, research facilitators, members of the Advisory Group and other contacts led to the identification of others who may have a role. These were a hospital chaplain, a ward administrator; a care manager in social work, a health visitor and, to add a different perspective, a voluntary sector counsellor. Though not working in a healthcare setting, the views of a counsellor were sought to clarify what is available for the bereaved in the community, and to shed some light on the long term difficulties that bereaved older people face. The recruitment of these individuals is discussed within the following sections in terms of their place of work: hospital; community; or care home sector. It could be assumed that the sampling frame for the study (Fig. 5, p 69) was fairly accurate in identifying the roles of staff who have regular involvement with bereaved older people.

4.1.1 Hospital wards and community hospitals

In hospital wards and community hospitals (see Table 8 overleaf) participation was facilitated at centres 1 and 3 by the ward sisters, at centre 4 by the head nurse at the hospital, while at centre 7 a senior staff nurse on the ward was able to support the research. Successful recruitment was in some cases facilitated by contacts made with hospital staff at a managerial level who were identified by the project advisory group. In contrast, contacts established through, for example, phone calls to community hospital switch boards were less reliable and did not necessarily lead to someone who would facilitate the research process. In some cases calls were directed to the head nurse at the

Table 8. Hospital recruitment

Centre no.	Centre type	Initial contact	Facilitator at centre	No. recruited	Roles
1	Hospital ward	Via advisory group member GBRIG	Ward sister	3	2 staff nurses 1 consultant physician 1 chaplain
2	Hospital ward	Via advisory group member	Nurse manager and ward sister	0	
3	Hospital ward	Via advisory group member	Ward sister	3	1 ward sister 1 staff nurse 1 nursing auxiliary
4	Community hospital	Hospital switchboard	Nurse manager	3	1 ward sister 1 staff nurse 1 ward administrator
5	Community hospital	Hospital switchboard	Ward sister	0	
6	Community hospital	Hospital switchboard	Nurse manager	0	
7	Community hospital	Advisory group member & area head nurse	Senior staff nurse	3	1 senior staff nurse 1 staff nurse 1 nursing auxiliary

hospital, while in others it was the most senior person on duty. Additionally, at a later stage in recruitment, contact with the area head nurse for community hospitals was extremely useful and provided good contact options. This led quickly to a senior staff nurse who had an interest in palliative care who made the decision that staff in her ward could take part and willingly facilitated recruitment. The range of roles of those who facilitated the research at their place of work indicated that when approaching a centre there was no clearly identifiable person to whom an initial inquiry should be directed.

In terms of medical staff in hospital wards, no junior doctors took part in the study. Their perspective may have added to the dataset as a group who have important contacts with the bereaved, however brief. However, a senior hospital doctor who was interviewed indicated that the nursing staff were the group who had closest involvement with patient's families at times of bereavement and that the input of any medical staff was minimal. Inquiries made to existing participants from hospital wards did not lead to any positive recruitment leads. In retrospect, there may have been opportunities to pursue this through other contacts.

4.1.2 Care homes

In contrast to the difficulties identified in facilitating the help of a key person in hospital services, at care homes approached to take part in the research this was straight forward. The home manager at all centres made the decision about whether or not staff could participate, and was the key recruitment facilitator (see Table 9 overleaf). Contacts were established through a colleague at the university, direct contact by phone, or via a member of the project advisory group. The colleague was able to indicate home managers whom she believed would be receptive to participating in the research. Her suggestions led rapidly to the recruitment of two homes in rural locations. Again making direct contact was less successful than finding out beforehand which homes may be receptive to the research. However, only one home manager from three approached in this way declined to participate.

There is a paucity of research in the care home sector, and consequently little was known about how staff would engage with research when initial approaches were made. However, it became apparent that taking part in bereavement research may have been seen as something that could help home managers to achieve objectives set for them by the governing body, the Scottish Commission for the Regulation of Care⁹. At centres 8 and 9, both managers indicated an interest in the research topic, and one manager spoke of palliative and end of life

⁹ Scottish Commission for the Regulation of Care <http://www.carecommission.com/>

Table 9. Care home recruitment

Centre no.	Centre type	Initial contact	Facilitator at centre	No. recruited	Roles
8	Care home, independent, rural	Lecturer, School of Nursing	Home manager	3	1 charge nurse 1 staff nurse 1 care worker
9	Care home, independent, rural	Lecturer, School of Nursing	Home manager	3	1 home manager 1 deputy manager 1 staff nurse
10	Care home, Church of Scotland, rural	Direct researcher contact	Home manager	0	
11	Care home, council, city	Direct researcher contact	Home manager	2	2 social care officers
12	Care home, voluntary services, city	Via advisory group member	Home manager	2	1 deputy manager 1 staff nurse

care being a priority area for development in care homes in Scotland. She was enthusiastic about taking part in the research on bereavement care to demonstrate that she was actively engaged in working towards increasing staffs' awareness of end of life issues, and in development of practice. A major aim of the study was to produce guidelines for bereavement care as practical application of the new knowledge (Landry, Amara and Lamari 2001). This was something that the manger saw as potentially useful for improving bereavement care in the home.

In terms of information collected from members of staff in the care home sector, it became apparent that local authority care managers have a key role in working with families in the lead up to an older person's placement in a home. Some mentioned an ongoing role for the care manager while the person was resident in the home and possible input with families in bereavement. Contact was made with a care manager and a meeting was set up with the aim of clarifying the

nature of the care manager's role and identifying any role in supporting bereaved families. It was explained that care managers are only involved with families for a short time beginning when a person is assessed for admission to long term care or for a home care package. When someone is admitted to a care home there is a further assessment after six weeks and if all is well the case will be closed by the social work department and there will be no further involvement of the care manager. When someone dies in a home the care manager should be notified though this is only for administrative purposes and instigates no follow up of the relatives.

The involvement of care managers with bereaved older people was further discussed with a colleague at the university who had recent social work experience. She did not see it quite so starkly and her thoughts were that when someone dies in a care home there may be further contact with the relatives if the care manager feels that there was a good relationship and that it was appropriate. These two points of view meant that it did not appear that there would be anything further to be gained from recruiting and interviewing a care manager.

4.1.3 General practice and community nursing

The key group to recruit as regards bereavement follow up were those working in community settings. However, recruitment of this group was challenging and various approaches were taken. Successful contacts were made through two members of the project advisory group. Service managers (head nurses) at the CHP also facilitated recruitment of district and community nurses. In addition, contact was made with a rural district nurse via a Practice Education Facilitator and a colleague at the university (see Table 10 overleaf). Two city GPs and a rural district nurse facilitated recruitment at their practices. The Macmillan nurse interviewee heard about the research through a service manager and volunteered to take part. Additional recruitment approaches were made by directly contacting a practice manager, to a GP by personal letter, and by directly contacting a Macmillan nurse who appeared to be interested in the work and willing to

Table 10. General practice recruitment

Centre no.	Centre type	Initial contact	Facilitator at centre	No. recruited	Roles
13	City centre general practice	From advisory group member, & service manager	GP	3	1 GP 1 district nurse 1 community nurse
14	Community Macmillan Nurses	From service manager	Macmillan nurse	1	1 Macmillan nurse
15	Rural general practice	Direct contact with practice manager	Practice manager	0	
16	Rural general practice	Personal letter	GP	0	
17	Rural general practice	Direct contact with Macmillan nurse	Macmillan nurse	0	
18	City general practice	From Advisory Group member	GP	3	1 GP 1 district nurse 1 community nurse
19	Rural general practice	From Practice Education Facilitator	District nurse	2	1 GP 1 district nurse

facilitate recruitment. None of these contacts were successful and delay in the project timetable resulted.

To explore a different means of recruitment, contact was made with Scottish Practices and Professionals Involved in Research (SPPIRe)¹⁰ to find out what could be offered in terms of supporting recruitment of practices. However, the SPPIRe co-ordinator suggested that GPs would require to be paid for their time. This may not have been cost prohibitive, but no other participant in the study received payment and it was undesirable to be seen to reward any one group.

¹⁰ SPPIRe website: http://www.sspc.ac.uk/documents/spcrnannualrep_05_06.pdf

However, incentives are often offered in clinical research studies and have been found to increase response rates (Lord et al 2003). Singer and Bossarte (2006) argue that rather than financial inducements that can distort perceptions of risk in research, the most important ethical concerns about participation should be provision of adequate information about the nature and purpose of the research, and protection of participants from harm. The three GPs who were recruited to the study did not require any payment and gave freely of their time.

Recruitment in general practice led successfully to GPs and nursing staff who clearly had input with bereaved older people. A further group identified as potentially having contact with the bereaved was health visitors. Efforts were made to talk to a health visitor to clarify the position via a colleague who had contact with health visitors for post registration education. Information was circulated about the project but no response was received. Contact was eventually made with a health visitor who was known personally who said that health visitors at her practice handed over responsibility for the older population to community nurses in 2000. She suggested I talk to a community nurse at her practice whose role was working with older people. Two community nurses had already been recruited and, though this nurse described her role well nothing was to be added by interviewing her for the study.

4.1.4. Bereaved older people

The fourth group of interviewees in this study was recently bereaved older people. In total six were recruited and interviewed and they provided a range of views and experiences. However, only two were identified by staff participants, one a city based GP and the other a rural district nurse. In addition, a ward sister who had facilitated staff recruitment provided contact details for two people that led to the recruitment of one person who took part in a pilot interview. Further participants were recruited via the GP advisory group member, a specialist nurse who takes part in GBRIG, and a city council run older people's group (see Table 11 overleaf).

Table 11. Recruitment of bereaved older people

Recruit no.	Centre	Initial contact	Interviewed	Reason not recruited
1	1	Ward sister	Yes (pilot)	
2	1	Ward sister	No	Phone calls unanswered
3	12	GP	Yes	
4	-	Specialist nurse	Yes	
5	-	Specialist nurse	Yes	
6	-	Advisory group	Yes	
7	-	Older people's group	Yes	
8	-	Older people's group	No	Withdrawal
9	18	District nurse	Yes	

Initially one person at a centre, a staff participant or a manager, was asked to consider introducing the study to relatives known to them. However, towards the end of the recruitment phase, when numbers remained low, all participants' help was requested. Some staff members said that they would not be able to help because they believed that approaching people with whom they had no contact for six months or more, on a sensitive topic like bereavement would be inappropriate. Others agreed to think about who would be suitable and some even had one or two in mind. However, the majority did not supply any names or contact details for relatives. Because recruitment of relatives via study participants was largely unsuccessful, other possible options were explored. The researcher met with two specialist nurse groups who were hospital cancer nurses and community Macmillan nurses to provide information about the study and to request assistance. This led to one specialist nurse (GBRIG member) identifying two potential participants who were subsequently approached, recruited and

interviewed. The remaining nurses in the groups were uncomfortable with the concept and indicated that pressure of work meant they would not have time to look back at records.

The recruitment strategy for bereaved relatives only worked when staff members had a particularly close relationship with a family. Both GPs who approached relatives had a relationship with the person over a long period of time as their family doctor. Similarly, the district nurse and the specialist nurse who made successful approaches had cared for the interviewee's spouses through their terminal illness and had built strong relationships with them at that time. This brought them to a position where they believed that it would be appropriate for them to approach the person about the research. It appears that there may be many other bereaved older people who would have had contact with healthcare staff who took part in the study or were approached to facilitate recruitment that were not identified as potential participants.

In a final attempt to augment recruitment an older person's group run jointly between the local authority and Age UK was approached. A visit to a meeting of the group was arranged where information about the study was provided and a request made for anyone interested in taking part to contact the researcher. This yielded two potential participants, one who withdrew before interview, and another who proceeded to interview. Again, recruitment procedures for bereaved older people yielded no clear pathway that led to people who were willing to participate and the potential for older people to engage in bereavement research remains poorly explored. The sample of older people recruited did, however, reflect a range of ages from early 60s to 93 years. All were spouses of the deceased, one widower and five widows. The wider implications of bereavement for older people who were parents, grand parents, siblings, friends, or had other types of relationships with the deceased were not therefore explored in the study. Identification of people who have non spousal relationships to the deceased may be difficult due to the mechanisms in healthcare systems for recording deaths, and the concentration on the spouse and closest family when a patient is at the

end of their life. In addition, the implications of the death for relatives who are perceived to be more distant, or friends, may be under appreciated by healthcare staff.

Far from being the systematic process that could ideally have taken place, recruitment proved to be more ad hoc and reactive. Recruitment to the study took longer than expected with consequent delay in completion of data collection and data analysis. In total 39 interviewees were recruited across staff and relatives: 33 staff; 6 bereaved older people (Table 12 below). Attempts to recruit hospital, care home, general practice staff and relatives in a distinct geographical area and treat them as a case were unsuccessful, and it became apparent early in the study that this would not be possible. A practice and a care home within a deprived inner city area were, however, recruited and provided staff perspectives and the views of a bereaved older person. The home was a council funded establishment though it was unclear how much alignment there was in the demographic profiles of the residents compared with the wider population of the area. The hospital serving the area is a large teaching hospital from which one ward was recruited. It would not reflect the demographics of the deprived area in question because it serves the population of the whole of region.

Table 12. Final recruitment numbers

Hospital	Care home	Community	Bereaved	Others
12	10	9	6	2

4.1.5 Re-engagement with the study outputs

The latter phase of the study involved re-engaging participants with the outputs of the study, the guidelines for bereavement care, to obtain feedback. As indicated in the previous chapter participants were invited to take part in focus group discussions, however, the response rate was poor. Table 13 (overleaf) indicates the numbers who took part in a focus group or individually provided feedback. Only five from 27 invitees indicated willingness to attend a focus group and three took part. Because one chose a different date and time from the

Table 13. Participants providing feedback on guidelines

Centre type	No. of staff invited	No. attending focus group	Roles	No. providing feedback separately	Roles
Hospital (city)	6	1	Chaplain	2	Consultant Sister
Community hospital	6	-		2	Admin Ward sister
Care home (city)	4	1	Deputy manager	0	
Care home (rural)	6	-		0	
General practice (city)	6	1	District nurse	1	GP
General practice (rural)	3	-		2	GP District nurse
Other	1	0			

others a separate meeting was held with this participant. Another participant was ill on the day of the meeting. A reminder letter achieved some response from participants but only to apologise for being unable to attend, though some gave feedback by phone or email at this time. Rurally located participants were contacted separately and feedback was received at a meeting or by phone or email.

Bereaved older people who took part in the study were also invited to provide feedback on the guidelines. However, only one participant made contact with the researcher and expressed willingness to participate at this stage. One participant was withdrawn from the study by a family member who believed the research to be causing unnecessary upset. No further contact was made with non responders.

4.2. Particular recruitment difficulties

Identified above are a number of difficulties encountered during participant recruitment for the study. Some further discussion follows to explore the issues that arose.

4.2.1 Healthcare staff

The engagement of a member of senior staff in a healthcare setting was found to be the key to successful participant recruitment. Support from a senior person facilitated positive response from staff to an invitation to participate. A barrier to recruitment occurred where the senior person entered into minimal discussion about the project with the researcher and did not provide support to staff. Recruitment may also depend on the personal characteristics of the senior person who acted as a facilitator for the research. In this study the facilitator often had a specific interest in palliative care, or in being involved in research.

Direct phone conversations were more successful as an initial approach than contact through written invitation or a gatekeeper, for example, a practice manager. Similarly, phone contact in a study that recruited healthcare staff, including physicians, to a mammography screening programme led to higher participation rates than introductory letters or mailed questionnaires (Lord et al 2003). Calls in the current study were always followed up by provision of written study information to those in agreement. MacDougall and Fudge (2001) recommend this type of approach that builds an information and negotiation strategy between the researcher and the potential participant. Negotiation was protracted in some cases and deferring making a decision about participation by contacts at study centres caused severe hindrance to recruitment in the project. This occurred even though effort was made at the initial approach to clearly indicate an expected timescale for recruitment procedures, and to identify a date for follow up contact that was satisfactory to each party. Being able to dedicate time to taking part in research was a common concern of healthcare staff approached, though there was little appreciation of the value of time as a

resource for researchers (Goodyear-Smith et al 2009). Time was also an issue for re-engaging with healthcare staff for feedback on the guidelines.

To take part in the study healthcare staff approached did not need to have specialist interest in bereavement. Selection was based on staff who may interact from time to time with the bereaved in their roles. However, managers approached tended to assume that participants should have an interest in bereavement or that participating centres should engage in a special way with bereaved relatives. In addition, negative response was received to invitation to participate when managers perceived no role for their staff post bereavement. In other centres managers tended to know who may be interested in end of life issues and would be more likely to participate. However, it was important to obtain the views of those who worked in a more generic way to provide bereavement care on an occasional basis to those families they interact with around the time of a death. In general the study sample achieved reflected this non specialised level of care, though the potentiality to omit this kind of perspective from the study sample was large. A particularly good example was a GP who took part but did not have a special interest in bereavement and described his contacts with bereaved older people as ad hoc and inconsistent.

4.2.2 Bereaved older people

The recruitment procedure approved by the ethics committee for involving bereaved older people in the research was at times a barrier in this study. Making contact with relatives was dependent on staff participating in the research. Steeves et al (2001) urged caution about using healthcare staff to facilitate recruitment of relatives. Though staff could approach people based on an established relationship they tend to restrict the autonomy of potential participants by subjectively selecting those they approach and those they do not and potentially biasing the sample. In this study, those who were approached and took part may be defined as 'good bereaved.' They were people in whom staff may have had some confidence that they would be more likely to react positively to an approach. A further difficulty compromising the recruitment

process was that most staff had not maintained contact with relatives after the deaths of patients in their care, and were unable to remember particular relatives. In addition, staff were often unaware of a relative's age and unable to define their eligibility.

The optimal length of time from bereavement to when researchers think it fit to ask relatives to take part in bereavement research is variable and no clear guidance exists (Stroebe, Stroebe and Schut 2003). Relatives taking part in the current study were bereaved between 11 months and 4 years, and two widows, both bereaved for about 18 months, said that they felt able to speak about their experiences now though would not have been previously. Beck and Konnert (2007) studied ethical issues in bereavement research and found similarly that bereaved individuals responding to questionnaires stated that they would not have been able to take part in bereavement research soon after the death. However, they felt that participation within the first two years was acceptable, though opinions varied on an optimal time within that timeframe.

The most ethically uncontroversial means of recruiting bereaved individuals to studies may be by informing potential participants via public media. This provides the opportunity for respondents to self select (Steeves et al 2001). However, there is the likelihood of recruiting a sample of bereaved individuals who are experiencing difficulties, and therefore not representative of the wider population (Steeves et al 2001). The sensitivity of the topic may also create a barrier to professionals' ability to actively engage with older people. There may have been a perception that people are reluctant to discuss sensitive issues that have affected them emotionally (Gledhill, Abbey and Schweitzer 2008). However, those who participated in the study willingly and openly discussed their experiences of being bereaved.

4.3 Data collection

Two forms of data collection were used in the study: in depth interviewing; and focus group discussion. In the sections below the practical application of the techniques are discussed.

4.3.1 The role of the interviewer

Interviewing is the predominant form of data collection in qualitative research, yet it has many challenging aspects. How well the researcher carries out the multi-faceted job of questioning, listening, and understanding determines the quality of the data collected. In addition, interpersonal communication and establishing a rapport with the participant are key to success (Morse 1989). In reality, however, interviewing was harder than anticipated and posed challenges particularly in terms of achieving consistency and quality. Co-constructed views were created but how near they are to real experiences may still be largely unclear (Rapley 2001).

Where participants were particularly welcoming or had a particular interest in bereavement rapport was easier to establish. Additionally, staff who had been in their posts longer, and showed confidence and openness in sharing their experiences, thoughts and opinions were easier to interview and reached a deeper level of engagement during the interview. However, most participants had never taken part in research previously and some were anxious about the process. Putting them at their ease was essential to allow them to contribute meaningfully, and full explanation of what the interview would entail was provided. In some cases this put them at ease, though some remained nervous throughout.

During the interview the job of the interviewer was to listen actively to responses, and to obtain more detail where necessary by checking out the meaning through additional questioning. In early interviews this was hard to achieve as it was often difficult to see where and when a further question should be added to open up the topic. There were also occasions where it seemed best not to interrupt

the flow of information with another question, and making a note of points that required probing may have been useful. However, it was difficult to be writing yet maintain active listening and interest in the participant. Morse (1989) also suggests that novice researchers tend to ask questions framed by their own knowledge, rather than the words of the interviewee. She identified reticence at following up statements with questions that paraphrase the participants' words to enable clarification of the point just made. This may have been the case in the current study, for example, bereaved relatives were asked how they coped with the bereavement when it may have provided fuller explanation if they had been asked to clarify what they meant by 'getting on with it.' A further technique used on two occasions to prompt interviewees was to provide some information about a personal experience of being with bereaved relatives. However, the examples used may have seemed extreme and inadvertently were interruptions to the flow of conversation. With experience and during later interviews, when effective techniques were identified and adopted the process became easier and interviews flowed better with perhaps more meaningful data being collected.

Across interviews many issues or topics came up regularly and, though possible, there is nothing to suggest that there were important issues that were not discussed. The level of detail may at times not have been optimal, however, between interviews, depending on the time available, recordings were replayed and field notes were reviewed to pick up on topics that needed more exploration in subsequent interviews. This was done with some success and notes were made on the topic guide as prompts to the line of questioning required. The end of the interviewing process was reached when no new topics were coming up in interviews and it could be determined that saturation had been reached. However, some topics that may have required further detail or testing out on other participants were only found when entering into the analysis stage of the project.

Perfecting the techniques of an effective qualitative researcher may be a lifetime's work, or at least would take many more interviews than were carried

out in this project, and to cover many more topics. The interviews carried out for this study, however, provided a large amount of data for analysis and a springboard from which the guidelines for bereavement care for older people were developed.

4.3.2 The practical process of carrying out an interview

Each interview followed a process that, though pre-determined was designed to be flexible, and was tested by initial pilot interviews that demonstrated how the planned activities worked in practice (Morse 1989). However, all eventualities could not be covered by the pilot interview, particularly as regards interviewing a bereaved older person. Wider piloting in the study was inevitably restricted due to the ethical dilemma of including people in a pilot study who may be emotionally affected by the topic.

Gathering informed consent from participants was an important part of the interview process tested in the pilot. However, a meeting with an older widow in the study demonstrated that at times the process restricted the quality of data collected. The interview took place in her home, and knowing the topic for the meeting, she immediately began to talk about her husband's death and her feelings. To obtain informed consent meant that she had to be interrupted so that the procedure could be explained and for her to read the consent form and provide signed permission. She needed time to do this and her initial flow of conversation was halted. Getting her to stop meant that the interview had to be picked up from a start point again when recording began, and she had to repeat some of the things she had already mentioned. In addition, the formal procedures and starting the recorder increased her anxiety.

Interviews lasted an average of 43 minutes, which was in congruence with pilot interviews and the estimated time given in the study information sheet. Effort was made to keep to time and in the small number of interviews that went over, participants were asked if they were happy to continue. It was important to stay true to the agreed time because most staff interviewees gave up work time to

take part and often alluded to having a tight schedule to meet. In interviews with relatives, the forty minute estimate was also adhered to as it was thought to be long enough for someone to be talking about something as personal and difficult as bereavement. Interviews could have taken place over more than one session (Wengraf 2001), however, this would have been more time consuming for respondents and for the research time table. Bereaved older people may also have been distressed by repeated interviewing.

During the recruitment process flexibility was offered to potential participants about when and where interviews took place (Legard, Keegan and Ward 2007). Interviews could have taken place on any day of the week, and at any time of day that was convenient to the interviewee. In reality, however, most interviews took place on a week day during the early afternoon, a time when there may be more staff on duty, particularly in hospital or care home settings. It was also preferred by bereaved older people. All interviews took place either in the place of work, or for the bereaved, in their homes.

As described in Chapter 3, the initial interview schedule and the later topic guide were used to guide the progress of interviews. In general, they guided progression through the stages of the interview in a logical order, but in reality they were harder to use than anticipated. Referring to the guide became difficult when maintaining eye contact with a participant, employing listening skills, and forming appropriate probes and prompts. In addition, a respondent often covered a number of topics on the guide in response to one question and it was difficult to re-engage with the guide at an appropriate place. In retrospect, after the first six to eight interviews it may have been possible to carry out the interview without the topic guide. However, having it to hand ensured completeness of the data collected and provided a reference point for returning to the topic when necessary.

The topic guides (Appendices 6 and 7) designed for the study were useful at leading the interview process and providing a path through different levels of

engagement with the topic. To set the scene the interviewee was asked to talk more generally about their background, and their present role. This highlighted key experiences that may influence attitudes towards bereavement, for example, one interviewee described being involved in designing an integrated care pathway for palliative care in a role she had previously held. The interview then moved to a deeper level of content mapping (Legard, Keegan and Ward 2007) where respondents were asked to describe their experiences of caring for bereaved older people. For some providing explicit detail of what was done, when and why was straightforward and they enjoyed recounting experiences, particularly if they had been involved with the family over an extended period. Others found this challenging and, even after probing and prompting there were some who could only discuss bereavement and bereavement care at a general level. This would appear to suggest that episodes of caring for bereaved older people become blurred and bereavement care was related to set tasks or roles that are carried out. In order to stimulate descriptions some experimentation with interviewing technique was carried out. In particular, some benefit was experienced in terms of generating further information and exploring potential enhancement of bereavement care when interviewees were given some insight into the researcher's research interests, professional background, and experiences. This made the researcher – interviewee relationship more equal and helped generate mutual trust and open discussion.

The mid sections of the interview explored participant's attitudes to bereavement and bereavement care and level of engagement with bereaved relatives. People were also challenged to think about gaps in services, what unfulfilled needs there were, and what could be done to assist the grief journeys of older people. This section of the interview was the most challenging for interviewer and interviewee. It required a questioning strategy that enabled respondents to explore their opinions and formulate responses. It was a process of thinking out loud that was prompted by an appropriate open question, and required probing to encourage development of thoughts. During the initial interviews phrasing of the questions was difficult, and confidence to probe may have been lacking. However, as more

interviews took place strategies were developed for asking the questions that elicited the information required. Response in this section was varied with some interviewees providing more in-depth thought and commentary than others. In a few cases it was obvious when respondents were thinking deeply and formulating a response, and for some the power of the process was personally enlightening.

The final section of the interview was designed to explore use of evidence based practice in the form of guidelines and protocols. This brought the interview away from the sensitive topic of bereavement to an area where practice processes were the focus. It was anticipated that people would be able to talk about this as users of protocols and guidelines. During the initial set of six interviews, however, it became apparent that most knew where they were kept at their place of practice, but engagement with them appeared to be poor across roles. This bore resonance with a previous research study that found competing demands on nurses and limits to their autonomy meant that implementation of evidence based practice is limited (Wilkinson 2008). This line of questioning was eventually abandoned as interviewees often appeared uncomfortable at their lack of knowledge.

The topic guide used for interviewing bereaved older people (Appendix 7) followed a similar format to that designed for staff. Participants were asked to begin by saying a bit about their day to day activities. This allowed them to speak about things that were familiar to them and to become used to the recorder and being interviewed. The main part of the interview then required respondents to speak about their experiences of bereavement and the bereavement care they had received from healthcare staff they had contact with at the time around their spouse's death. Participants all told their stories very well and with a high level of detail. Some had prepared hand written notes prior to the interview taking place and referred to them periodically. Some probing was required to obtain additional detail that completed the picture. Detail was, however, lacking when respondents were asked about the involvement of healthcare staff around the time of the death. Most said that the time had been

confusing for them and they only had vague recollection of what particular members of staff said to them, or did for them. Being clear about what aspects of their contacts with healthcare staff would constitute bereavement care was difficult for the bereaved older people interviewed. The interview ended with some discussion of how bereavement care could be enhanced, and what kind of things could be done additionally to help family members cope with a death. Participants found it challenging to come up with suggestions without being clear about what was already provided. A more general line of questioning to finish off with may have been appropriate after this section, as at times it felt that the interview did not have any clear ending. However, on most occasions the conversation rose to a more general level and finished with a subtle move away from the topic area.

4.3.3. The interview situation

The field work for the study provided two experiences that were entirely unanticipated and demanded careful management and decision making. On one occasion an appointment was arranged to interview a trained nurse at a community hospital. A colleague, an untrained nurse had also agreed to take part in the study though had said that she did not want to be interviewed on a one to one basis. She had indicated on her response form that she would take part in a group discussion, the later phase of the study. On arrival at the hospital both participants said that they were prepared to be interviewed and said that they would both take part in a joint interview. It was stressed that what is said in an interview is confidential and that this could only happen if they both agreed that they would not mind the other hearing their responses. They gave consent and it was decided that the interview could proceed. The dilemma for the research was how much the different management of this interview would affect the quality of the data. It was decided that it should be included in the analysis as its content included at least one topic that had not been raised by other interviewees. The two interviewees may have influenced each other at times in what was said as they both had cared for the same families. However, they also described experiences in different roles and previous positions.

The second incident of particular interest involved an interviewee who was a trained nurse in a care home. She had just returned to work on the day of the interview after having been off following the death of a close family member. She was asked how she felt about taking part in the interview and it was suggested that it could take place on another day. She seemed to suddenly remember the topic of the interview and said that she had not really thought about it but that she would be alright. It was again reiterated that the interview could take place at another time but she was insistent that she would be fine and wanted to continue. There was nothing about her demeanor that would have indicated otherwise so the interview continued and she engaged well in the topic, though her recent experience of bereavement influenced her responses. In particular, she was able to achieve a deep level of thought and opinion formation regarding possible enhancements to bereavement care.

Recent personal bereavement was a feature for more staff interviewees and may have been a reason for them volunteering to take part. It may also have been a reason for the person who facilitated the research at the site identifying that person as someone who may be able to take part. The personal dimension did appear to help participants to think about the needs of bereaved older people beyond their experience through their work. This is not to say that those who did not have recent personal experiences were unable to consider bereavement in detail. A particularly difficult personal experience, however, led to one interviewee becoming upset.

Upset also occurred for a care home nurse who talked in detail about bereaved relatives that she had supported. Her involvement with people at the home took place over long periods of time and she became extremely close to residents and families. She spoke in great detail about a particular family, to the extent that tears welled up in her eyes and, for the listener there was also an emotional affect. This demonstrates the importance that people place on interactions with bereaved families, and on providing appropriate care and support. The bereaved older people who took part in the study showed remarkable resilience and,

though emotions were raised, they did their best to respond as fully. Most shed tears at least once during the interview but were able to continue, some after a short break.

4.3.4 Focus group discussion

Focus group discussions have been previously used to collect data that aimed to develop and validate guidelines on communication and end of life decision making for GPs (Deschepper et al 2006). Practitioners in the field gave feedback that, in common with the aims of the current study, allowed finalisation of a version for use in practice. Chapter 3 outlined the methods employed for re-engagement of study participants for this second phase of data collection. The group discussions were, however, poorly attended (see Table 13, p 114) though all who did take part had a high level of interest in the topic and were motivated to assist with the development of a suitable tool. Representation was achieved from the three practice settings of interest and the group discussion enabled participants to make sense of their thoughts, and the researcher to compare and contrast views (Barbour 2005). The main advantage of using the focus group in this study was that the power imbalance between the researcher and the researched was reduced and participants openly discussed issues with each other (Barbour 2005). Participants were sufficiently engaged in the topic to make efforts to be constructively critical of the guidelines enabling them to be improved. There appeared to be minimal reticence created because the guidelines had been developed by the focus group facilitator.

Discussion in the group was well focused and the guidelines, as well as the topic guide, were used to maintain the attention on critical analysis of its contents. Strengths and weaknesses of aspects of the guidelines were discussed from the point of view of respondents' roles, though the range was limited. Over the hour of discussion many issues were raised and participants gave insight to the reasons for developing and holding their opinions (Barbour 2005). When data was analysed it was identified that thoughts generally arose from experiences of being involved in caring for older people and bereavement care. For example, a

participant viewed older people as reluctant to accept offers of support and, relating this to the guidelines, she identified difficulties with follow up criteria suggested. Practical issues, for example, staff training and resources were also discussed in the group and allowed thought to turn to implementation in practice. Data collected from the group was used to redraft and finalise a version of the guidelines that could be introduced to healthcare settings.

Carrying out the field work in this study was an enjoyable and informative experience that provided a valuable practical education in involving practitioner groups and bereaved older people in research. The lessons were many and varied, as indicated above, and will form a suitable platform from which to build and conduct future research proposals and studies. In addition, the thorough descriptions of recruitment and data collection will assist in demonstrating the credibility and external validity of the data analysis that will be reported in subsequent chapters of this thesis (Marshall and Rossman 1999). The next two chapters of the thesis focus on the findings of data analysis. Firstly, results of the interview study are presented (Chapter 5), and this is followed by reporting the development of the guidelines and the findings of the consultation on the guidelines (Chapter 6).

CHAPTER 5

RESULTS OF THE INTERVIEW STUDY

This chapter presents the results of analysis of the interview data collected in the study from staff in the three practice areas and bereaved older people. The aim of collecting and analysing the data was to explore and provide explanatory accounts (Spencer, Ritchie and O'Connor 2007), of current care provided to the bereaved. Four themes were identified through indexing, coding and interpretation of data in the interview transcripts:

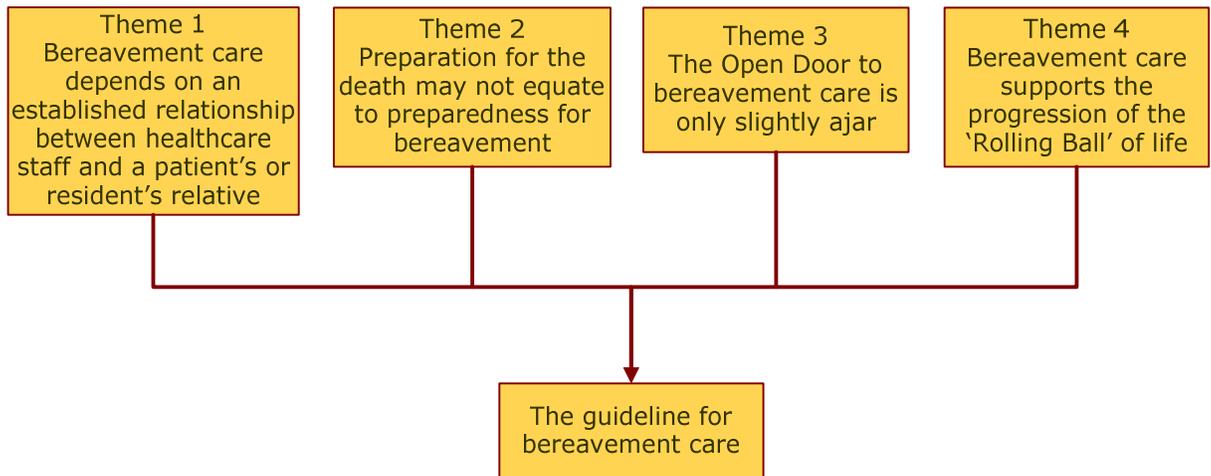
- Bereavement care depends on an established relationship between healthcare staff and a patient's or resident's relative;
- Preparation for the death may not equate to preparedness for bereavement;
- The 'Open Door' to bereavement care is only slightly ajar;
- Bereavement care supports the progression of the 'Rolling Ball' of life.

Each theme, though independent, contains elements that may have resonance in others. Participants' stories extracted from the phenomenological analysis of interview data are used in the chapter to illustrate the themes. Important points about bereavement care are raised in the examples and are further explored in the thematic analysis. To maintain the voices of the study participants in the analysis and subsequent development of outputs from the study the texts and quotes presented were derived verbatim from the transcripts. Minimal editing took place with the sole purpose of reducing the length. The analysis led into and informed the development of the guidelines for bereavement care for older people (see Figure 7 overleaf).

5.1 Bereavement care depends on an established relationship between healthcare staff and a patient's or resident's relative

Interviewees in the three healthcare staff groups in the study described bereavement care as being dependent on having an ongoing relationship with a patient's or resident's family. The relationship develops from the time that the ill person first comes into the care of the staff member. When the patient or

Figure 7. Analysis of interview data informing development of the guidelines



resident, relatives and staff are facing the terminal stage of illness can be the time when the relationship develops to become therapeutic and supportive. The established relationship then facilitates preparation of the relatives for bereavement, support at the time of the death, and for some, support in the days and weeks afterwards.

I feel that if you build up a relationship with them and allow them to speak, then afterwards they are going to feel quite comfortable and would be willing to speak to you. District nurse, city practice

Across the interviews staff said that follow up bereavement care should be provided by the professional who has built up the best relationship with the family, and this often comes about through caring for the deceased. Community nursing staff described a relationship with families through which they become aware of possible post bereavement needs of relatives.

Whoever's been dealing, or had the most input with the family is obviously the one that will do the bereavement visit. They'll know how things happened and how things progressed and you can judge when they are at the terminal stages, how the family are going to kind of cope and how much they'll need, how much kind of input and support they'll need after. District Nurse, city practice

This means that appropriate support can be provided as a natural progression of the relationship. The relationship also allows both supporter and the bereaved older person to feel comfortable and be able to talk openly. Relatives in the study also suggested that bereavement care would only be helpful if the member of staff was known to the patient and relative, and had knowledge of the care of the patient in the lead up to death.

You know, you've got to have some sort of almost relationship with the person, whereas a, just an almost anonymous person phoning from the hospital saying, 'I've been going through the list of people that have died and I've come to you, you're next on my phone list, are you managing OK?' No, that's nae use, that's nae use at all.

Widower, 60s

Carol's story (Box 1 overleaf) describes the experience of a community nurse of building a relationship with an older couple. Carol was an experienced nurse who believed that to holistically care for a patient to the end of their life included caring for their family. She cared for and supported the terminally ill patient to the end of his life, and his wife through the end stages of her husband's illness and into bereavement. Pre bereavement visits were to a large extent about building a supportive relationship with the patient's wife. Being informed about her husband's illness, included in making care decisions and able to talk about how she felt throughout meant that she was able to cope with the transition to bereavement.

Bereaved older people may potentially have a range of needs at different times in their bereavement journeys. Figure 8 (page 132) indicates how the relationship with healthcare staff facilitates supporting activities that respond to needs, but also arrives at a point where the relationship ends. The bereavement care pathways indicated depend on the established relationship, placed at the top of the figure. Pre bereavement the relationship is used to provide opportunities for relatives to anticipate and prepare for the death of their spouse or other relative.

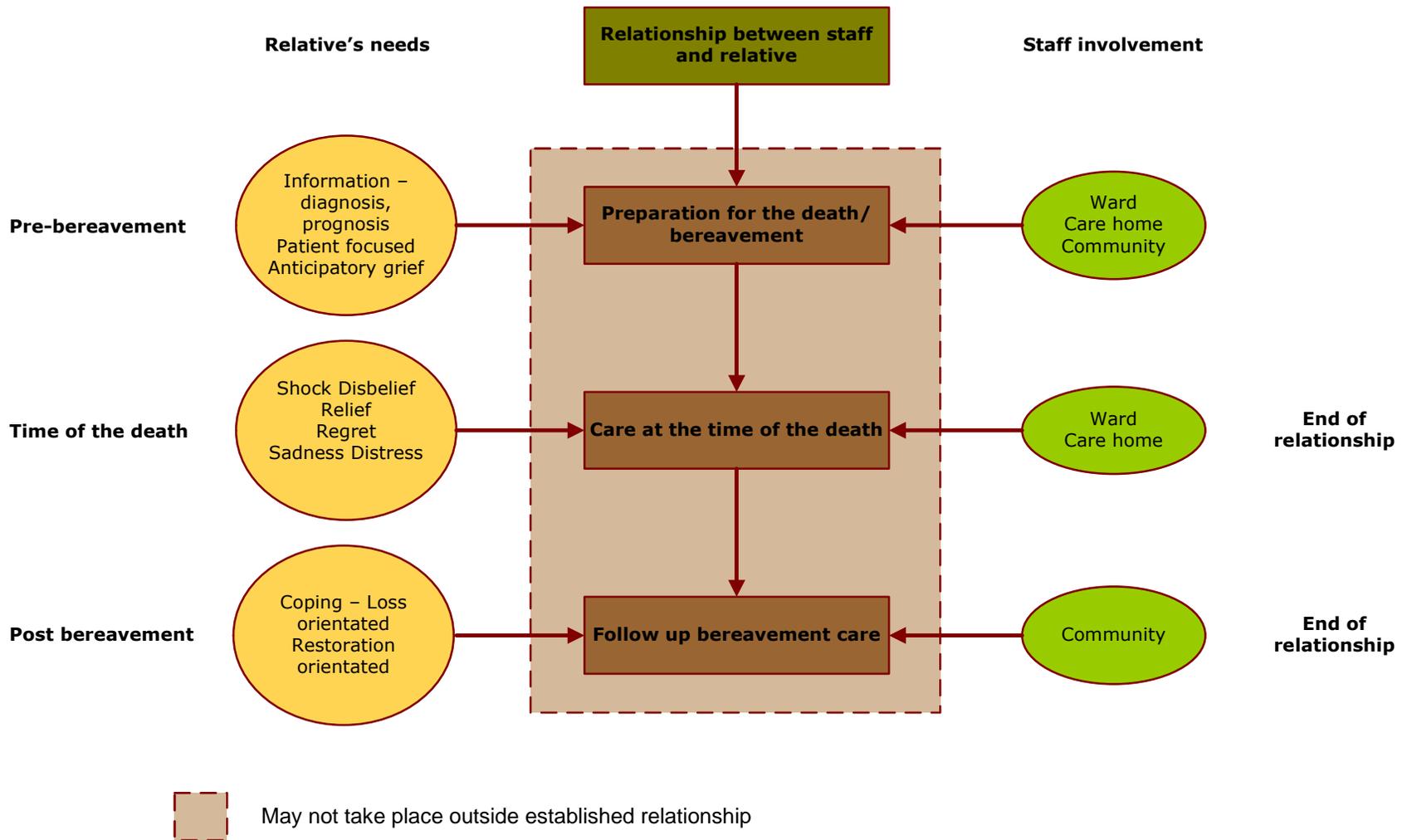
I mean, that's the ideal, when you've got folk who are coming in regularly, its letting people know when somebody's deteriorating and

Box 1. Carol's story

I remember an elderly couple (dying husband), well she was in her late 80's, he was in his 90's. They were very private about everything and it was sort of breaking down the barriers you know to get them to accept help from us. We were there to support both her and her husband and getting her to open up because all she would ever say was that everything was fine. We used to go in weekly to see him because he was on (medication) and that sort of broke the barriers. I engaged them both in conversation to help them to understand. She never thought he was going to die, she just thought his illness would just sort of progress for a long time. They thought that after he'd had his operation that was the cancer all gone, they never sort of picked up on it. She was quite a frail nervous person and we got the doctor involved to break the news gently and we were there to support, to catch her and pick up the pieces so that they understood what was going on.

We'd go in weekly, we'd go in and see her just to make sure that she was coping and things like that and emm, as his illness progressed we increased the visits and then we had the night nurses. She still wanted to do so many things, ken like, herself. We just guided them through the journey, and I think her transition was much easier because we had sort of introduced her to it all and kept her so well informed and she found it so much easier to speak. If she was worried she would speak to us whereas before she would never say anything. Then when he died she was just so grateful and, everything went so well and it gave her so much peace of mind. When we went to see her after she was able, she could do all these things, she could go out with her daughter and things like that and she was able to live again with no regrets.

Figure 8. Relationship between healthcare staff and bereaved older person



to give them the chance to come, to see, to ask questions and prepare them. Deputy manager, care home

In hospital and care home settings, the established relationship leads to support through the emotional turmoil that people experience at the time of the death.

I suppose more often than not we're seeing them from the time they come onto the ward, if we know somebody's quite unwell, right the way through that person deteriorating and passing away. I think for nurses, it's probably easier for us to perform the bereavement care and assist them because we know them and we have seen them so frequently. The families do tend to look to you for that extra bit of support and guidance. Staff nurse, medical ward

In the community, though pre bereavement support is provided to patients and carers, the staff may not be there at the time of the death or the patient may have died in hospital. However, there is the opportunity to provide follow up bereavement care that the other staff groups are restricted in providing.

I think we're quite good here at visiting patients afterwards, I know the doctors visit immediately after, within the next sort of day or two days. If it's an elderly person and they're registered with us you can usually always find reasons to go back and fore and visit them. District nurse, city practice

Depending on circumstances surrounding the death there may be no opportunity for pre bereavement preparation, care at the time of the death, or follow up. This may be the case when, for example, the death was sudden, links with a patient's or resident's relatives are poorly established, or relatives are registered with a different GP from the person who died. The bereavement care pathways indicated in Figure 8 may be inconsistently followed, or not followed at all. This is indicated by the shaded area in the diagram. Ward staff described caring for bereaved relatives after a sudden death, or a death that takes place soon after a patient is admitted. Suddenness means that the opportunity to get to know the family, their wishes and coping styles, may not be available. In addition, it is harder for staff to reach a satisfactory conclusion for the relative, or for

themselves, through interactions. There is no clear impression of having done all that they can to support the relative, and they return to caring for others regretting not being able to offer more.

Any problematic issues that we have had here have been about people that are newly admitted and died more suddenly. You almost feel that it's a bit, frustrating's not right, but it's a bit cut short because you haven't developed any rapport with the relatives and it just seems very much, not failed in some way, just feel that they're maybe left wanting. You don't feel maybe as fulfilled if that's the right word, maybe done as much as you'd have liked. Manager, care home

Follow up then falls to community services and is carried out within the established relationship between a GP and a relative, or as relatives in the study indicated, not at all. However, when the death is not unexpected there may not always be a guarantee of follow up bereavement care either. A widow who was in her 80s, whose husband had suffered long term illness and had died in hospital said, *I cannae mind a doctor coming to see me fae the surgery or anything.* Though GPs recognised that contact was important to relatives they were still extremely variable in bereavement follow up practice.

After death we try very hard to identify whether or not there are relatives that are known to the practice and where there are we will make contact with those relatives in a bereavement visit if you like. Now, I know that while we try to do that it doesn't always happen. It's not unusual for different family members to be registered with different general practices and therefore that's a difficulty. GP, city practice

GPs interviewed saw inconsistency in bereavement care practice as a failing and attributed it to administrative issues, pressures of work and perceptions of optimal care.

I'm not sure that there is the resource currently in place to allow us to do it to the extent that perhaps we might need to do it, and that resource is not just a financial resource. Well, it probably is the case

that the general practitioner is not the person to be providing bereavement support. GP, city practice

In addition, community nursing staff believed it to be inappropriate to carry out bereavement visits with people whom they had not known previously.

We wouldn't be called in to see someone that we hadn't actually been providing care for. I've never been asked to see someone just for bereavement care. District nurse, rural practice

Providing emotional and practical support at the time of the death is shrouded in rituals in hospitals and care homes that lead to a place where the relationship with a patient's or resident's relatives can be brought to a conclusion. The relationship, while it exists, can be intense in nature, though there is an understanding between staff and relatives that it will end at some point after the death. Hospital ward and care home staff, in particular, reach an ending very close to the time of the death (see Figure 8).

We find here that when somebody does die it's the last contact we have with relatives. Senior staff nurse, community hospital

Community staff may continue relationships with the bereaved for a period of time afterwards by providing follow up support but again seek a satisfactory ending. In community settings, however, there may be the opportunity to end relationships at a time that is agreed to be therapeutically beneficial for the bereaved older person. A community Macmillan nurse discussed her follow up contacts with an older widow:

She was very keen for me to keep seeing her but really what it boiled down to was for some social contact, it wasn't, you know I saw her bereavement as normal. I saw her up to about six or eight weeks after he died but as a professional you have to be aware of 'should I be continuing this, am I the right person, actually what are the needs here?' Actually I think she was just adjusting, and I think perhaps during her husband's illness her own social contact had shrunk a bit so it was about trying to re-establish that, and I talked

about that with her and so we agreed that I wouldn't come back again, but I did phone her about a month later.

An exit from the episode of bereavement care may be negotiated in a way that appears to leave options for re-entering the relationship should there be a need.

I would always say, 'now that you're much more abler and you're going out and you're seeing people again, its maybe time that I left you my contact number. You've got my contact numbers so if you ever need me you just contact me'. Community nurse, city practice

The ending of the relationship also appears to give staff permission to turn to caring for others in the ward or home, or on the caseload and the process of caring for other patients or residents and building bonds with other families continues.

It would be unusual in this day and age for us to undertake repeat home visits to bereaved relatives. Certainly in the inner city now that cannot happen because of the pressure of work. GP, city practice

There is, however, some frustration in ending the relationship abruptly and a desire to ensure that people are supported where necessary.

I feel frustrated sometimes that we can't follow them on. We have information, contact numbers like Cruse, but often to be able to follow them on at home and see them settled back in at home and support them there. But I mean, we have to stop somewhere and that's where you hand over to the community teams, the GPs and district nurses. Sister, community hospital

Concern was expressed, particularly in hospital services, that providing follow up would entail a time consuming process of identifying all bereaved relatives and friends and the possibility of following up an unfeasibly large number of people.

How do you define who are the bereaved people? And then you've got friends because obviously friends are bereaved as well. You have maybe got close friends who are closer than the family, and that's again a resource issue you know. Consultant, medical ward

In addition, it was recognised that not all bereaved older people would need or want follow up support from healthcare services. A staff nurse in a community hospital warned that *'sometimes you've got to watch because nae a' relatives want people at them.'* In addition, relatives are not patients, and that poses a dilemma about what can appropriately be done to support or to facilitate ongoing support.

Often it's difficult for us because we are in the hospital environment, you can only do so much with relatives because technically they are part of your remit but once they leave the ward they are not your patient, so it makes it a lot more difficult for us. Staff nurse, medical ward

In effect the relationship ends when the relative leaves the care establishment. However, the effects of bereavement described by older people are multi-faceted and may last for many months or years.

In hospital or care home settings supportive relationships may develop between trained nurses and patient's relatives. In addition, they often exist between the relatives of patients and residents and untrained nurses or care workers regularly seen providing care.

Some of the nursing assistants that are here are so experienced and they have maybe known the person and the person would maybe rather go and speak to them. Staff nurse, community hospital

This kind of relationship and knowledge of the patient or resident and the family are key to providing support at the time of the death and at times into bereavement. However, supportive relationships do not happen universally and only one widow in the study described such a relationship. Another widow experienced dissatisfying contacts with hospital and community staff, poor communication in the lead up to her husband's death, and only one nurse in the ward where he died perceived as giving regard to her loss.

There was one staff nurse on the ward that (husband) died in and he was the one who always came in about and put a hand on my shoulder. He was the only one that sort of realised there was

something you know, and the sister on the ward was very nice but she was always so busy running about, but this chappie... On the morning that he died and I went up, it was him that took me through to (husband) and everything and I just felt that he was in sympathy with me. Widow, 80s

The relationship with bereaved older people also holds challenges for healthcare staff. A close bond may lead to a situation where being with the relative is upsetting for the staff member. This is particularly apparent in care homes where the staff and residents often become like friends or family members.

I mean, the majority of relatives do think of us as being an extended family to their people that are here. Social care officer, care home

At the time of the death there is then a need to create a balance between showing emotion and remaining in control of the situation. Staff have different attitudes to expressing emotion with families with some believing that shedding tears shows care, while others wish to maintain composure to support the family. Contrasting views are given in the next two quotes.

I've got no problem with (supporting bereaved relatives) at all. No, because I cry with them. Staff nurse, hospital

You dinnae want to get upset in front of them, that's the challenging bit, its keeping strong and emm, finding the right words. Trained nurse, care home

Staff may express mutual loss by attending the funeral, writing, or sending a sympathy card.

The key workers and named nurses would always have the opportunity to attend a resident's funeral. For a lot of staff it puts a bit of closure on the whole care package that they've offered that person, that they can, you know they're at the funeral and they can share some of the memories and some of the grief. Manager, care home

I always write, probably within the next eight weeks. I wrote to someone recently, a letter asking how they are, you know

acknowledging that it's so many weeks since the death. I look through the photograph albums and I take out some nice pictures, put the pictures in and say 'found these, thought they would bring back some nice memories of the times you shared in the home.'

Manager, care home

Where staff are involved regularly with end of life care they believe there is a need to protect themselves from too much emotional expression.

I think that you can get close but at the same time you have to protect yourself as well because as I say we do quite a lot of palliative care and if you're, if you allow yourself really to get too close it can be quite emotionally difficult. Senior staff nurse, community hospital

Debriefing and open discussion in some work places provides an opportunity for staff to talk about the relationship with the family and how the death has affected them. This relates directly to implications of experiences within the context of providing ongoing care for other patients and residents.

I think as nursing staff we support each other quite well, we'll do, in a situation where it hasn't gone well we'll review the whole case and things like that. It helps you to get closure because its quite difficult at times on an acute ward because you may be dealing with a palliative patient and their relatives and things like that and then you have to come out of the room and you have to go onto maybe the minor injury unit. Ward sister, community hospital

5.2 Preparation for the end of the relative's life may not equate to preparedness for bereavement

The relationship between healthcare staff and the relatives of patients and residents, as described above, forms the basis of support around the time of the death. It is inextricably linked with the processes that are entered into to help relatives to prepare for the death of the ill person. Preparing the relative for the loss, and facilitating the process of anticipatory grief is a large part of a healthcare staffs' role in the lead up to an expected death.

In situations where people have had the chance to prepare for the death, say in palliative care or long term chronic conditions, my feeling is that we have a role to actually make sure that people are preparing for this because often it makes things a little bit easier at the bereavement phase. GP, city practice

I think we do give, we do give a lot of good bereavement care here in the ward as much as we can, with information and being there for the family, accommodate the family and just hopefully getting things in place to help the patient and the family to cope with the death and have a peaceful death which is very important as well. So bereavement care before the death. Staff nurse, community hospital

However, the preparation process is multifaceted and may not mean that relatives are ready for the death or bereavement. Joanne's story presented in Box 2 overleaf explores the complexity of preparing relatives for the death of someone close. Joanne is a ward sister in a community hospital. She described working with the daughters of a dying patient who were reluctant to accept that their mother was dying. Though the focus of this study is older people, the experiences of caring for the younger relatives described illustrates a number of issues that could occur in other situations.

The story demonstrates the difficulties of communicating effectively about death and bereavement with dying patients' relatives. Constant dialogue between the family and healthcare staff did little to prepare them for the inevitable death. Other staff interviewees, particularly in hospital settings, also described relatives being in denial of the reality of the situation. For example, a staff nurse in a community hospital said, '*some people can maybe prepare where others maybe can't. They can still be in denial.*' Breaking down the barrier between staff and relatives was the key to preparation and in Joanne's story another family member was used to facilitate communication. This, however, did not lead to a level of preparation that allowed the death to be accepted by the patient's daughters. In addition, it is unlikely that they were prepared for the challenges of bereavement.

Box 2. Joanne's story

We had a young woman, she must have been in her 50s, she was a single mum with two grown up daughters. She was with us for quite some time, about two or three months. The girls were finding it very difficult to cope despite having the Macmillan social worker involved. There was a bit of denial there. The (palliative) suite was made into like a cocoon, a shrine. They took up residence there and kind of moved in and weren't leaving mum. They found it really quite difficult to accept the dying process and the bereavement. They weren't keen to listen to the medical staff and the nursing staff, and I think there was a great barrier there in the denial that their mum was going to die. They just wanted to protect their mum and keep their mum with them.

That was a particularly hard one because their laundry was in the room and they had more or less moved in. I feel that they were trying to close the outside world out and hold things as they were in that time scale. It was very difficult to talk and discuss things with them because they just weren't prepared and ready to listen. You were there constantly with them but the nurses still found it quite difficult to communicate with them. I think the thing with them was, the saviour, one of the mum's sisters came along, an aunt. She kind of acted like a link, knowing the girls well and she would get them to understand things better. They were more prepared to listen to a member of her family than to a member of the medical or nursing staff.

It was horrendous when the patient died. They, the girls were really upset and crying, I mean they wouldn't leave their mum. Oh it was tragic for them, it really was.

Staff interviewee's experiences of preparing relatives for bereavement were varied. Additional training and experience in palliative and end of life care increased staffs' awareness of the needs of relatives and their confidence to engage with them and to support colleagues.

I felt (palliative care training) would benefit the ward with just some more in depth knowledge of palliative care and all the different things, the issues that go along with it that I feel sometimes can get missed a bit. Like the social aspects of things and family, bringing the family into things as well. Its not a palliative unit as such, the GPs are general and sometimes it's fine just to be able to give a bit of support and suggest. Staff nurse, community hospital

Other staff, though engaged with relatives in the lead up to a patient's or resident's death, may wait for cues from the relative before offering information.

You tend to talk about things, you tend to be driven by the person in front of you, the relative's agendas and where they are at emotionally, where they're at, how much they want to ask about.

GP, rural practice

There is, in addition, a tendency to assume that people are well informed if they don't ask questions.

The thing is, ye only broach that kinda subject (death and bereavement) if they broach it wi' you, and if they do broach it wi' you ye ken that they're worried about it and things like 'at. Because otherwise they've got a'thing sorted oot and that, but a lot o' them do ken, a lot of them are aware and they ken fits coming.

Community nurse, city practice

In general, preparation focuses on medical aspects of the patient's condition and information is commonly provided in terms of the diagnosis, prognosis, withdrawing of life support measures, and symptom relief.

I think, well you have to be perfectly honest with them about what's going on and what's happening and whether people are going to recover or they're not going to recover and how things are going to go, particularly in palliative care. GP, city practice

We discuss not for resuscitation forms, the medical staff discuss that with them obviously. The relatives sometimes approach us and say that they don't want any intervention now, or sometimes the medical

staff say that they want to speak to the relatives and they don't feel that its appropriate to you know ... Staff nurse, hospital

This allows the relative to begin to anticipate the loss and may mean that they enter the grieving process before the death has occurred. A widow in the study whose husband died following a long period of illness was prepared for his death by talking with the GP and community nursing staff. She was able to grieve her loss with her husband before he died.

It still is a shock when it comes, but I think we baith had gratten as much afore hand, it is, its nae easier but at least you are prepared a bitty better I think than if he had just died, I think it would have jist been an awful tragedy then. Widow, 60s

Facilitating this process, however, depends on the staff recognising that the patient is in the end stages and honestly conveying the facts to the relative. Staff described barriers to communicating this kind of information when relatives maintained hope for the patient's recovery. They believed that it was inappropriate to dash people's hopes, and when talking with relatives try to put emphasis on hoping for a peaceful death.

It's often difficult if communication's not handled properly. (The relatives) are ill prepared for the terminal stage, living in hope that there's going to be something. Then its harder for them to accept their bereavement as well because they always go on looking for hope when they should actually be, if everybody was communicating properly, then they would be told that there is hope but in a dignified death, and their symptoms and pain are managed. Ward sister, community hospital

Good communication is essential for preparing relatives, and those in the study had different experiences in the lead up to their spouses' deaths. The widower in the study described only getting information when he asked questions of medical staff. For him, knowing what his wife's death may be like was particularly useful.

One thing that I found difficult was the 'what's going to happen, how is it going to go?' And I can remember once or twice trying to phone

the Macmillan nurse just to say 'hey, you've seen this before what's the maist likely, what am I going to have to build mysel' up for?' Aye, would she gradually fade away or would she start taking fits, would she take a heart attack or would she go unconscious etc. etc? All of which not knowing made it far more difficult to sort of plan ahead for and you know, it was 'am I going to cope with this that's ahead of me?' Eventually I plucked up courage and I asked her GP and one of the options he thought was that she might go back and start taking fits again and that's actually what happened. Widower, 60s

In addition, a widow experienced being told bits of information by different healthcare staff that painted, in her view, a confusing picture. Medical staff also put a positive spin on the situation and she hung on to false hope for her husband's recovery.

I wasn't (prepared) because he wanted to come home and I had a new bed bought and up in the living room because the toilet was next door to it, and I'd everything ready to take him home and I'd told the staff and they said 'well wait until New Year and you can take him home in the New Year,' because he wanted home. He couldnae walk really because his hip hadnae healed. Widow, 80s

In the long run she relied on her own observations of his condition and implicit signs like him being moved to a side ward that led her to realise that he was at the end of his life. Another widow in the study related a similar experience and said, '*I used to watch his urine bag you know, and it was getting darker and darker, so I knew it was.....*' Staff, however, described experiences of working with relatives who were unwilling to enter into discussion about an impending death.

We have others who really really don't want to talk about it, that feel that when they talk about it that it'll make it happen sooner or that they just can't cope with the thought of mum dying and they just don't want to speak about it. Deputy manager, care home

They may wish the focus to remain on their ill person and the main concern to be for their comfort.

I feel that if the relatives see you doing your best for the client, their mother or father or brother or sister or whatever, then they get comfort from that as well. Ward sister, community hospital

In addition, relatives were unprepared for the death when they had not been involved in care decisions, and had been unable to maintain some control of the situation. A widow whose husband had been admitted to hospital near the end of his life, and against her wishes said, *'I just had to give in, and he was sent to (hospital). I really wasn't happy with the care that he got there.'* She wept at this point in the interview, when speaking about the end of her husband's life and events that had occurred. Staff, however, believed that when the patient has been well cared for and their wishes respected, their relatives can more readily accept the death and cope with bereavement.

It's a good death for the relatives if they are prepared for what's to come and everything is done as well as it can be, then you might not get a bereavement reaction and bereavement becomes a lot easier to get through. GP, city practice

In the lead up to a death healthcare staff described a further role in helping patients or residents and their relatives to clarify their wishes for the time of the death. When wishes are known at an early stage in the caring relationship, it may negate the need to ask awkward questions at the death.

We look at (death) as a normal part of the living process in this home. You know we need to know how people like to go to bed or get washed and dressed, it's the same. Some people desperately want to be with a loved one when their condition deteriorates. Some people don't want to be contacted during the night. We have all that information prior to a decline. Deputy manager, care home

Patient's or residents may themselves take a lead in ensuring that their wishes are known for the time of their death. A hospital staff nurse described a patient with a long term condition who is, *'quite open about speaking about her funeral,*

about the time that she goes, as she wants to make sure that these things happen.' Communication takes place about whether relatives want to be called during the night, what the patient would like to be wearing when they leave the ward, and whether a burial or cremation is preferred. This allows staff to ensure that wishes are respected and procedures are dealt with smoothly at the time of the death. The GP below described additionally encouraging families to be practically as well as emotionally prepared.

Its very important that everybody knows exactly what's going on because there's things that need to be done, things that need to be said while people have got an opportunity to do that and they shouldn't be put off. Particularly, say in younger patients who have family commitments and stuff, you know the legal financial side of things are really quite important and can be quite complicated. That's not maybe preparing folk for bereavement but that's getting through, in a way it's a sense of the inevitable coming. GP, city practice

Though staff try to provide information alerting relatives to the imminent death, there appears to be less engagement in preparing relatives for bereavement, as indicated in the quote above. This may be harder for staff to broach and it may also be harder for them to identify possible effects. There are few examples in the study of staff talking with relatives about bereavement prior to the event. However, a GP in the study described flagging up for relatives the possibility of the time after the funeral being challenging.

I suppose the thing we probably do talk about is the time after the funeral. I always see that as just the month or two after, there's just this big potential dip time. Just to sort of say 'just watch, you may think that you might be coping OK but don't be surprised if you find that after the funeral that really things become sometimes very empty and bleak.'

Preparation is, however, focused on the care of the patient or resident and the reality of their imminent death. How bereavement will affect them remains an

unknown quantity for older people until they experience it for themselves, and a suddenly bereaved widow said, *'its just such an awfa' loss you know. Ehh, I never really thought about it before although he had been quite ill quite a lot you know, I just never ever thought it would be as hard as this.'* However, the myriad of experiences that the older people in the study identified as elements of bereavement suggest that knowing all that lay ahead may be problematic and possibly unhelpful. Some examples are quoted below.

My biggest problem is I'm alone. I mean if I took ill there's nobody to look after me. Widow, 90s

I get miserable you know, I get mis...I worry myself terribly and get miserable but I cannot actually, I cannot actually get the tears. Widow, 80s

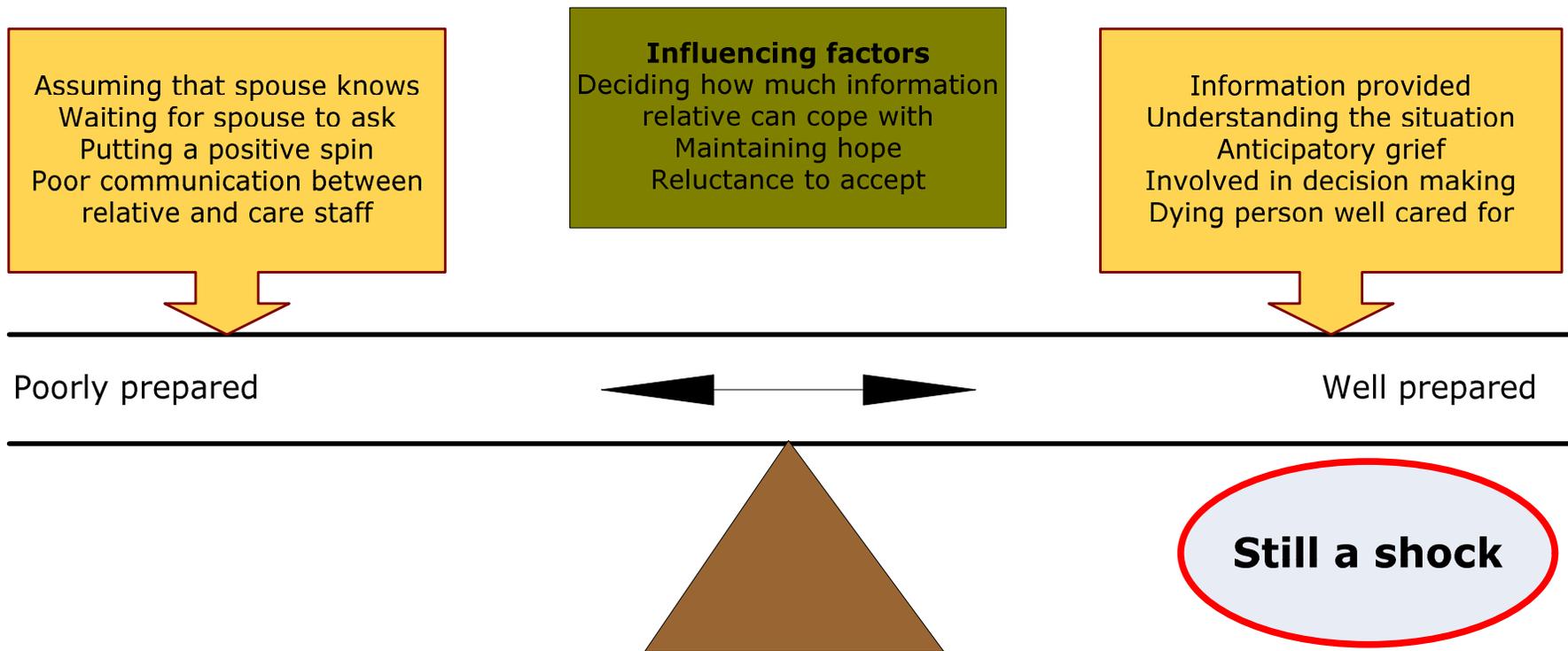
The maist difficult thing, as (friend) says, is the first birthday, the first anniversary and the first Christmas, right. I agree, aifter a' that wis past it began to ease off, you began to kind o' look forward. Widower, 60s

In addition, staff and relatives interviewed believed that no matter how much preparation there has been for the death it still comes as a shock. People find themselves without their life partner or other close relative and bereavement is a frightening and bewildering experience. An elderly widow described her reaction to her husband's death:

I couldn't take it in, I didn't believe it. For a long time afterwards I didn't believe it, and his presence is still here. I mean, I don't want to leave my, I won't go into a home, I've told (son) that I won't go into a home. I said, 'I don't want to go into a home, I want to stay here because (husband's) presence is still with me.'

Figure 9 overleaf demonstrates the balance required to achieve a measured preparation for normal bereavement. Factors described above influence where on the continuum a relative may lie before the death, and for most a combination of factors influence the preparation. Overall, preparation of older relatives for the death of their spouse or other relative generally lies somewhere at the centre of

Figure 9. Measured preparation



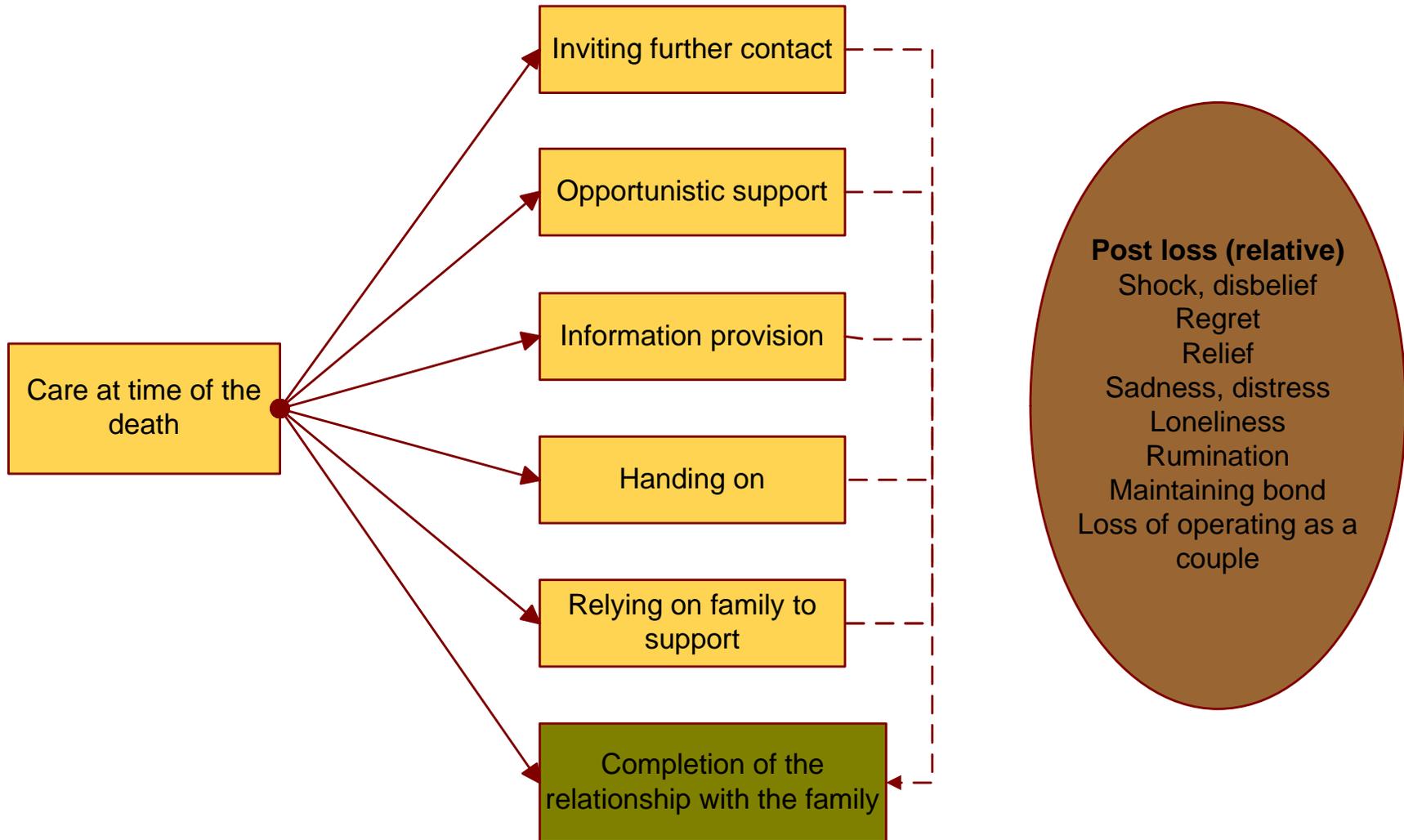
the poorly prepared – well prepared continuum. The optimal place to be on the scales may appear to be at the well prepared end of the scale. However, the data suggests that the death may still be a shock, and that it may not be ameliorated by the amount of preparation.

5.3 The Open Door to bereavement care is only slightly ajar

In 5.1 it was identified that the death of the patient or resident generally signifies the ending of the relationship, particularly from hospital ward or care home staff. Staff, however, are aware that older people may have questions they need answered, events that need clarification, or other support needs in the weeks and months after the death. As a result they are willing to take steps to ensure that bereaved relatives have information and a means of reaching back into the service. A GP interviewee referred to the provision of contact details and an invitation as '*offering an open door of support for future, over the coming days.*' The analogy of the 'Open Door' is used in this section to describe the various strategies, including giving contact information, that are employed to assist relatives to find support when they have needs (see Figure 10 overleaf).

The 'Open Door' provided by healthcare staff has five main elements: inviting further contact; opportunistic support; information provision; handing on; and relying on the family to support. Inviting further contact and opportunistic support allow further discussion of the death and bereavement if necessary. However, the remaining three are less defined opportunities though could also be supportive. All five demand little staff engagement in terms of time and resources and are convenient ways to validate any further contact and interaction in terms of the bereavement. They are linked in their common goal of providing additional support, however, also in allowing the relationship with the family to be ended. The interview data presented below has allowed some exploration of the degree to which the range of experiences of bereaved older people is addressed by the 'Open Door.' The literature review presented in Chapter 2 identified that bereaved older people face challenges from emotional effects related to their loss, and in adapting to their new circumstances and self identity.

Figure 10. The Open Door



This is also reflected in the interview data and participants explained the challenges they face in finding ways to cope with their loss and to carry on living without the support of their partner. Some of the effects of bereavement on an older person that interviewees identified are included in Figure 10 in the oval on the right. This section explores what is provided in terms of follow up care from healthcare services that there may have been contact with around the time of the death.

5.3.1 Inviting further contact

Staff are aware that the time of the death may not be the best time at which to give relatives lots of information. They described giving contact details for the service to enable people to reach back in for further explanation. Hospital ward staff in particular, provide a card with the contact details of a named person who was there at the death and aware of events leading to the death.

We've got information packs, we always hand that out with obviously the nurse that was on with them at that particular point when their relative passed away and the phone number for the ward. So they've always got a name and a number to contact us back and they've got the information there because often they don't take in what you are telling them at that point and its later on when they've sort of calmed down a wee bit after the shock of it and they think 'I never asked that question' or 'What do I do there?'. Staff Nurse, medical ward

The type of support offered by hospital staff through this open invitation is, in general, about clarification of events that led to the death and practical arrangements after the death. However, there was little knowledge of the type of needs people may have later in bereavement and what may be required during an interaction. There was also little experience of anyone making contact after a death so no knowledge base from which to draw.

I haven't had anybody phone myself, but one of my colleagues has been telephoned, but it was just something that wasn't much to us but it was obviously something to him. He was just asking if it was,

you know, in her sleep or, you know it was just on his mind. Staff nurse, medical ward

Care home staff additionally support older relatives by inviting them to visit the home where they have built up friendships with staff and other residents and families. They are aware that bereavement brings loneliness and social isolation for many and wish to continue to provide them with social and emotional support.

When somebody's died and we've had the funeral and the family are clearing out the room we always say you know, you're welcome any time to come in and you know have a coffee and a chat, any time at all. Sometimes, well mostly people, families do come back once or twice. Social care officer, care home

For some who are perceived as being particularly socially isolated contact may be more regular.

We have relatives that will come up once a week for lunch, Friday's the fish day. We have a lady who comes, whose husband is no longer here, she comes routinely for lunch. I don't know if we do anything else but it's just kinda 'hello and how are you' but I suppose its an important part in her week as well. She knows that on a Friday at 12 o'clock she's coming in to the home. Manager, care home

Coming back to the home, however, where there are associations with the dead relative may be more difficult for some than others.

Now and again they'll come in. Some people feel they need to come because it was such a part of their life, and then other people feel the need to come and then when they come and their folks aren't there its too hurtful, its too sad for them. Some of them won't come for a long while because they can't for that reason, and then they'll come a bit later. Deputy manager, care home

Staff interviewed described a number of examples of people who made return visits, some for many years after their relative's death. Some also became

involved in volunteer work at the home, and one home manager described a resident's relative supporting other families in the lead up to a death.

She's obviously feeling that 'can I put something back into a service that was perhaps lacking for me and maybe help people where I didn't have that support?' And I suppose you know it keeps in contact with where her (relative) was looked after, she maintains the ties and has lots of nice memories and we speak about her (relative) regularly when she's here and you know, get out the photographs and remember we did this.

GPs and community nursing staff also provide open invitations for relatives to approach them for further support. GPs believe that people will only come after bereavement if they are experiencing difficulties.

If we are seeing people coming in after funerals rather than us having arranged it or anything, then there is a problem you know that needs to be dealt with. People don't come unless usually they've struggled with it themselves for quite a while. You really have to take that seriously because they've come to see you for a reason and you need to work through that with them. GP, city practice

Additional support or intervention, therefore, may only be necessary when the relative is having difficulty coping with their loss. In addition, this kind of need may only be recognised some time after the bereavement when contacting hospital services does not seem appropriate any more. The GP, where a long standing relationship probably exists, is then the first point of contact. Reaching back into GP services for follow up contact may, however, pose difficulties for the bereaved older person in negotiating the system. Gaining access via the practice receptionist to even leave a message for the GP is a particular barrier.

Where that sometimes falls down in a big practice is, can they get past the receptionist? Some of us will say get back in touch, leave a message, and there's certain various rules been created for when you can leave messages, when you can't leave messages and things

like that, emm on the computer. Sometimes what a practice does can be a barrier. If you've got a very vocal elderly person, someone whose not, whose quite confident in themselves and not frightened to say 'well Dr Xxxxx told me to get in touch,' they're fine, they'll work through that system, whereas the wee sheepish one will just go 'oh no, I'd better not bother him then.' GP, rural practice

People therefore feel that they have to provide another more valid reason for seeing the doctor. In addition, when they do arrive in the consulting room they may go through a process of testing out whether the doctor is willing to engage with them on bereavement.

I think its very rare that someone will come in and say 'look I've been bereaved, I'm really struggling with this.' They'll usually come in more with, it might be just like 'I'm tired, I'm so tired all the time,' they're maybe depressive kind of symptoms or other kind of physical problems, but which are almost manifestations or almost excuses. An excuse and I say that in a nice way, which are validations to be able to come in and talk about things and I suppose it's the patient's way of testing to see if you're the kind of person that wants to listen to them or not. I think patients tend not to come direct and say 'look I'm really struggling with this bereavement.' You've usually got to scratch away at something to get them to talk about it. GP, rural practice

If this is the reality of looking for bereavement support, then unsurprisingly relatives in the study feel that they are left to cope with their grief as best as they can without the support of healthcare staff.

Relatives in the study also had no experiences of contacting services again, though they may have had informational or support needs. They described a determination to work their own way through bereavement and did not identify healthcare services as places where they would look for support.

I think I got leaflets like where I could ask for help and things like that, but it's such a confusing time ye ken, ye just try and cope and

dae the best ye can yersel' really. I felt like, being quite an independent body, I think I just went along and did the best I could and just tried to cope. Widow, 80s

Another widow who had no acknowledgement of her loss from her GP, appeared to believe that healthcare services were not interested in bereavement unless there was a crisis.

I suppose if I had gone to pieces there would have been doctors and that there. Widow, 70s

Other sources of support were considered rather than reaching back into healthcare services for support. The widower below sought support from a friend who had been spousally bereaved in similar circumstances.

I often wondered about phoning him, however I didnae because I was a wee bitty worried about opening up old wounds, I didnae ken how he would feel about it. In retrospect, when I did phone him, 'Oh ye should have phoned me earlier.' It was aifter (wife) died and I asked him about how he coped after (his wife's) death, he telt me the things that he had done wrong. Widower, 60s

5.3.2 Opportunistic support

Participants in the study described informal meetings with bereaved relatives that provided opportunities for them to see how they are getting on. These types of encounters often take place in public places, for example, supermarkets or village streets. Staff valued these encounters when they could share sympathies or reminisce about the patient or resident. Families may also reiterate their appreciation of care staff at this time. For care home staff there will additionally be some conversation about life at the home.

We don't really see them again unless they're local and we see them in the street. Now that I've been here for so long, I meet a lot of them and they'll say 'are you still at the nursing home?' So you have that bit of contact. Deputy manager, care home

However, no therapeutic value was attached by healthcare staff to such meetings.

It's a relatively small town, you're down town, you meet people and they stop you obviously and you have a chat and say how are you, but that's nothing. What are you getting at that time, is it really how they are? Senior Staff Nurse, Community Hospital

Conversely, people who have had bad experiences at the time of the death and may be more likely to have follow up needs may not approach staff. Staff also may not approach relatives with whom the relationship was difficult. A ward sister in a community hospital talked of a bereaved woman who had been distressed by the death of her relative,

I sometimes see her when I'm out but there's no recognition or anything and I think she tends to walk to the other side of the street. It had been an episode in her life that was still maybe too painful for her to work through at the time, or still is.

Contact with bereaved relatives could also be opportunistic on the part of the GP and bereavement concerns arise unexpectedly and sometimes a long time after the death.

Yesterday there was a lady come in for something, she'd had a fall and she just mentioned something about her husband who'd died a couple of years ago. We got into conversation and she was great from my point of view because you saw my day yesterday¹¹, but what she made me do was stop and listen to her and she had a really sad story but I think we probably both got a lot out of talking about it. She said something and I could have just ignored it but she's a really nice old lady and I asked her more about it and I think it was probably helpful for her. GP, rural practice

GPs who are willing to engage with bereaved relatives described looking for opportunities to 'keep an eye' on those they may have concerns about. The same GP as above described contriving the opportunity to follow up a widow about whom he had concerns by walking his dog past her house and calling past to see her.

¹¹ He had seen between 40-50 patients on the day previous to the interview.

Occasionally I've taken the dog for a walk past and I've seen her out in the garden so I've just chatted with her and you see that she's getting by, she's OK and I know that if she wants something, I know she'll get in touch with me.

In addition, a city GP perceived elderly men who have lost their wives to be particularly worthy of the extra vigilance.

There are one group of patients though that I do think are particularly vulnerable and that tends to be elderly men who lose their spouse. He has been totally reliant often on his wife or partner to do certain things like meals and house keeping and all the rest of it. Suddenly he has nobody to do that and older men I think, and I think the literature says this, that they are particularly vulnerable. So we tend to keep a closer eye on them in the first few months after bereavement, just to see how they are doing and I would usually want to see them one or two months after just to see how things are going.

GPs try to be accessible while allowing people to get on with their lives without intervention. Subsequent visits to the surgery for other reasons are particular opportunities to enquire how a widower is getting on, as well as enquiring of other family members when they attend. There are also occasions when concern is sufficient to warrant inviting the bereaved older person to come to the surgery for a follow up consultation. Depending on the GPs knowledge of the person a formal appointment will be given, or it will be informally tagged on to another reason for the visit, for example, blood pressure check.

I would want to see them again and I would make a note to sort of, if any of their family were in to say 'how's your dad getting on, how's your grandfather getting on', and just sound out how things are generally going. Having said that, these guys tend to do OK if they've got a very supportive family, but not everybody does now that's the thing. GP, city practice

Community nursing staff also use this kind of checking up behaviour by disguising visits as collecting notes or equipment after the death.

Ye really jist go in, quite often you're gan in maybe to pick up notes, pick up stock that's nae langer needed, things like that. Ye're jist gan in to see how they are. Community nurse, city practice

In addition, though perhaps more legitimately, the opportunity to provide support may come about when a community nurse learns of a bereavement when carrying out routine elderly assessment.

Ye'll jist say, and usually I eiwis ask how lang they've been widowed ken and jist take it fae there.

Being able to talk about bereavement a long time after the death is seen as a key requirement for community staff as they engage with their patients.

5.3.3 Information provision

Staff in wards and care homes routinely provide relatives with information about administrative arrangements that take place after a death.

The nurse who's been looking after them will come in and discuss things with them and give them the information pack, tell them when the certificate will be given. Emm, if they've never dealt with a death before we can go through and say, you know, it's the undertakers you need to contact, and then you'll get the certificate, and go down to the registry office and go through it with them.

Staff nurse, hospital ward

Again, the amount and type of information provided may depend on the relationship and perceived knowledge of the relatives and how they operate. Staff may not wish to sound patronising, though at the same time try to be helpful.

Depending on the relatives and how well you know them or whether, again it very much depends on their ability and whether they want you to intrude, you know because sometimes it can seem an intrusion, other times they want support, but telling them all the

things that need to be done or recommending an undertaker. Social care officer, care home

Information is given in oral and in printed formats, or both, depending on staffs' preferences and perceptions of how older people receive and use information. Interviewees described variable provision depending on what they believed particular relatives needed and availability.

I always take time and speak to them, I never hand them booklets or anything like that. I like to tell them verbally what's happening. It's what to do after they die as regards funeral arrangements and what they have to do, practical things because a lot of them have never had to do it before. Even however old they are, they've never had to arrange a funeral or anything like that before and they are completely lost. Staff nurse, hospital ward

Some staff, however, believed that relatives are reassured when they can take a booklet or leaflet away with them.

What we try to do in the hospital is to give practical help, so if somebody say's to us, 'I'm not sure what to do about registering a death, I'm not sure about what to do about organising a funeral service, I'm not sure about how do we tie up a person's estate.' We've got booklets that we give to people and from our own experience we would also try to point them in the direction of where they might get the help. Chaplain, hospital

The time of the death was considered to be a less than opportune moment for giving detailed information, and written information meant that relatives had something that they could look at later.

Often they don't take in what you are telling them at that point and its later on when they've sort of calmed down a wee bit after the shock of it and they think 'Oh, I never asked that question' or 'Oh what do I do there?' We do try our best to give some, a point of contact with ourselves or the information booklets sort of give you a run through of what happens after a bereavement in Scotland. So at least its handy to have, because often leaflets help a lot better don't

they? You can read through it and, 'Oh yes,' you've got it right in front of you. Staff nurse, hospital

The level of information provision across services varies dependent on the staff member who is present at the time of the death. As explored above, some willingly spend time verbally explaining procedures and taking time to answer questions while others hand out the booklets with little explanation. Both styles may implicitly infer that the ward or home has done all that they can and the written information can be consulted for further guidance negating the need for further contact. In addition, the provision of information may be given as a support to self care. However, relatives in the study indicated that though they had the information they may not find it accessible or useful. The following quote from a widow, used previously to illuminate older people's use of their personal resources to maintain independence, also indicates some reluctance to engage with written information.

I think I got leaflets like where I could ask for help and things like that, but it's such a confusing time ye ken, ye just try and cope and dae the best ye can yersel' really. I felt like, being quite an independent body and I think I just went along and did the best I could and just tried to cope. Widow, 80s

5.3.4 Handing on

A key objective of the study was to explore the interface between services regarding bereaved older people. Where there were concerns that could not be dealt with in a particular service a requirement to consult others was apparent. A charge nurse at a rural care home identified that bereavement may be a cause for concern for some older people and would consider communicating with other services, though did not specify which services may be useful to contact:

We would make sure we did something about it. We wouldn't just say, 'oh well, that's fine, out of our care now.'

Others developed ideas during interviews about whom it may be most useful to contact in particular circumstances. Social work input was seen as particularly

helpful for older people, and is readily contactable in care home and hospital settings, as demonstrated in the two quotes below.

I mean if you were really concerned I would maybe contact, because everybody, they've all got care managers. So you could contact a care manager and say 'Mr so and so's not coping, his wife or his mother's just died.' Social care officer, care home

Our social work department here is very good so if there was any issues that we felt somebody, probably if they were, the person that had passed away was the main carer for that person they would be in some sort of accommodation, getting assistance at that point so then it would really just be taken over in a sense by social work, they would, or the care managers they would then take over the role of how they would manage to look after that person. Staff nurse, medical ward

GPs were also believed to be in a position to provide further support to newly bereaved relatives.

If I thought they were in shock or... I would certainly be, even phoning if they weren't local even asking if they wanted their own GP or even seek advice from our GPs, definitely. Trained nurse, care home

A GP interviewee cautiously identified communication with them about concerns regarding a bereaved older person as helpful.

What I would say is that where a need has been identified, so that if the hospital identifies worries about some relatives, clearly there would then be, it would be useful for that degree of concern to be communicated to the general practitioner or perhaps some other agency. But I don't think we should automatically assume that just because bereavement has happened that there would be a need.

GP, city practice

However, throughout the study practitioners were unaware of any communication, or did not themselves communicate concerns about bereaved relatives to other services.

We've nae contact with the GPs or the district nurses or anything like that at all. Maybe its something you should, but then again we don't do it, have never done it. Staff nurse, care of the elderly ward

Figure 11 overleaf traces communication links across services about bereaved older people. In particular, being located within a hospital or care home was a barrier to communication or contact with other services, for example, general practice and community nursing. Communication that does take place is currently at the level of notifying the health centre of the death though there was no clear idea of what was done with the information.

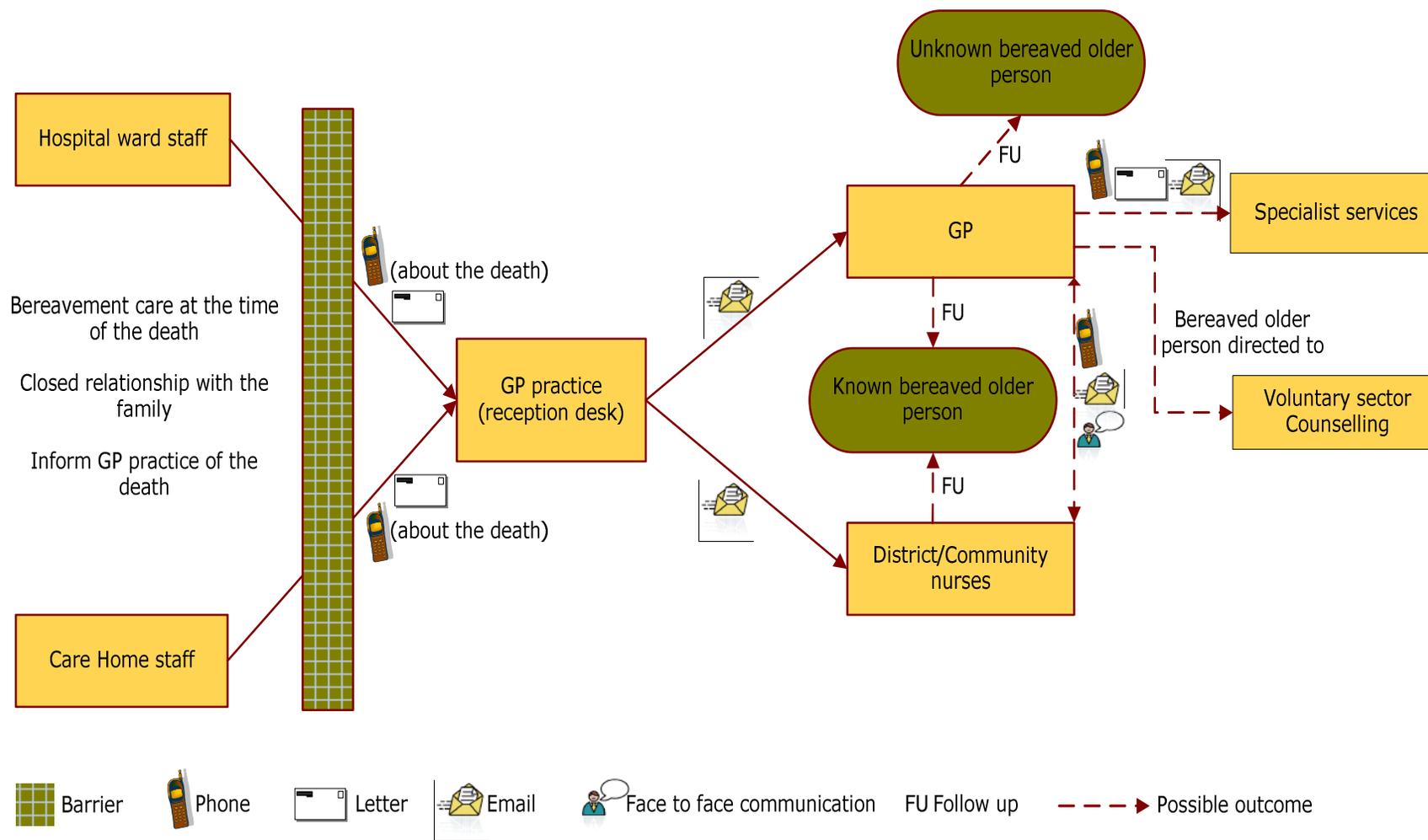
I would have hoped that if we informed the GP and they've got a widow or a widower that they would speak to the community nurses or at least go and see them themselves, I would have thought but I actually don't know. Staff Nurse, community hospital

Interviews with general practice staff revealed a complicated system of disseminating the information round GPs and community nursing staff. It is then up to a member of staff who knows the family to decide whether or not a visit would be necessary. People fall through the net when they are not known by any practice staff or registered with a different practice from the deceased.

We all get an email round all the clinical staff just saying such and such has died and it gets put in the visits book, the day book and we all have a look at it. There is no failsafe mechanism then making sure someone does something about that, its left to all of us as individuals to look after it and for someone to go, 'yes, I know that person, lets go and do it,' but there may occasionally be folk who everyone goes, 'oh no, I don't know them,' but assumes that someone else is doing it, and actually we don't have a failsafe... GP, rural practice

When relatives known to practice staff are followed up in bereavement some communication may take place between GPs and community nursing staff if there are concerns (Figure 11).

Figure 11. Communication about the bereaved



I think the only communication would be between myself as a GP and probably my district nursing colleagues. There would probably be some sort of conversation, that would be the extent of it. GP, city practice

GPs may go on to refer bereaved older people to other services, for example, mental health. However, it is more usual to suggest voluntary sector agencies or counselling services to relatives and leave it with them to decide whether or not to make contact.

I have a patient waiting to see somebody at Cruse. We might just give them the number to contact and say well this is why we think this would be appropriate, maybe you'd like to go and see them. Then it puts the responsibility on to the patient to go and do something. It can actually lift them out from a phase to actually do something about it and that in itself can be therapeutic. GP, city practice

Cruse, however, may not be seen as a useful service for older people. The following GP viewed it as somewhere he may recommend for younger bereaved people.

For younger people there are services like Cruse available where certainly I've recommended younger people should consider going. I don't think I have ever recommended that an elderly bereaved person uses that service. Maybe it's a bit of me that also feels, well its part of getting older and I don't, I certainly don't recognise that the likes of Cruse makes itself particularly available or readily accessible by the elderly population.

However, a relative interviewed had experience of Cruse and had found it beneficial.

I think when it happened, maybe a couple of weeks after, I actually phoned Cruse. I had a one to one for two weeks and then the group started up, so that's the group been going about 8 weeks. I think this week's the last week of it, but then I'll go back to the one to

one. I think the group has really helped me in understanding that other people are feeling like this as well, nae just me. Widow, 60s

Relatives may also be signposted to sources of support for practical difficulties. Financial concerns were seen by one community nurse as a challenge for bereaved older people, and she described being proactive in suggesting where to look for assistance.

If they're having financial difficulties I always direct them to the Benefits Agency and they'll come out and see them and help them sort through all the paperwork and things like that, and that's a big thing because it's a huge burden to them. Community nurse, city practice

However, there was no indication in the study that bereaved older people were routinely directed to suitable sources of information and support. A widow identified form filling and dealing with finances as a major difficulty as this had been previously a role taken by her husband. She had been given no clear information about where to find help.

I believe I could have got help fae the, it used to be in (street), I don't know if they're still there or not, welfare rights is it, welfare rights? I'm nae sure. Somebody said I could get help there but by that time I'd maist o' it done anyway.

Overall the data indicates that communication links regarding bereaved older people appear to be incomplete at a number of points and there may be a risk that people with problematic grieving remain unidentified.

5.3.5 Relying on the family to support

The factors of the Open Door that are described above, in some way, invite contact but also inhibit opportunities for healthcare staff to support bereaved older people. Healthcare staff believe that family members will support each other, validating the tendency to withdraw at an early stage.

To be honest I think the best bereavement service you will ever get is your ain family. OK, fair enough speaking to an outsider, that can

help, but an outsider cannae support you in the same wye.....I mean your family's the best line of support you're ever going to have.
Care worker, care home

Staff are reassured when older relatives have been supported all along by other family members and assume or hope that the support will continue.

If the family are in and they're all together, we tend to, I suppose you tend to leave it with the family members to counsel each other in a sense. Staff nurse, hospital

You find that a lot of them have families that will look after them once they are out of this situation. Staff nurse, hospital

Relatives in the study experienced low level follow up support from healthcare staff and also described their families as their support network. They each found support that did not involve additional follow up from general practice or community nursing staff.

I've got a fairly close circle o' (family members) who are almost surrogate brothers and sisters. They have been kind of very supportive and very helpful and I've used them to sound off till.
Widower, 60s

Particular concern was expressed by staff for those older people who have no family left and there was awareness that bereaved older people had complex social situations that were often exacerbated by the loss.

Because it is, when that person is dying or is coming to the end they are surrounded by the doctor, nurses, district nurses and even if they are in here and we're here to support. Once that person has gone you're on your own apart from your family, but there's a lot of people have no family. Trained nurse, care home

It's the social isolation, the cutting off from certain friends, maybe friends of the husband or the wife. People fall away and you get sometimes quite isolated at times because they maybe often are, physically aren't able to go out and mix and things like that.

Sometimes with, families are far flung they often don't get the visits from the family the same either. Ward sister, community hospital

A hospital chaplain, in addition, had concerns about whether or not bereaved older people would be adequately supported emotionally by their family. He feared that it may be too difficult to speak openly about bereavement and that there is reluctance to put pressure on others in the family who were also bereaved.

Often they won't talk to family members about how they're feeling because that's too difficult. Its almost like saying, 'I'm going to put on you the responsibility for this', and they don't like doing that so often they'll hide it and they'll internalise it. They swallow the emotion down inside and eventually it gets to the point where it breaks out somehow, and it can break out in so many different ways and that's the dangerous thing.

Community nursing staff appear to be more proactive in supporting an older person who is coping with bereavement alone and, provided there has been an established relationship, continue to visit.

If it's an elderly person and they're registered with us you can usually always find reasons to go back and fore and visit them.

District Nurse, city practice

However, while this may be the aim of one district nurse, others may differ in their practice.

We do a bereavement visit but that's more of less as far as the contact would go and it would be left up to them possibly to contact us through a relative or through a GP. District nurse, rural practice

The risk remains that there may be older people in the community who are coping with bereavement alone and remain unsupported.

The Open Door is challenged on many fronts by the way it is facilitated by staff in all the healthcare settings in the study. At times it appears to be open and welcoming, for example, when making contact with services is invited. Other

elements like poor communication links, however, are simultaneously closing it off. The data analysis suggests that the door may only be slightly ajar and difficult for bereaved older people to access, and for healthcare staff to open wider.

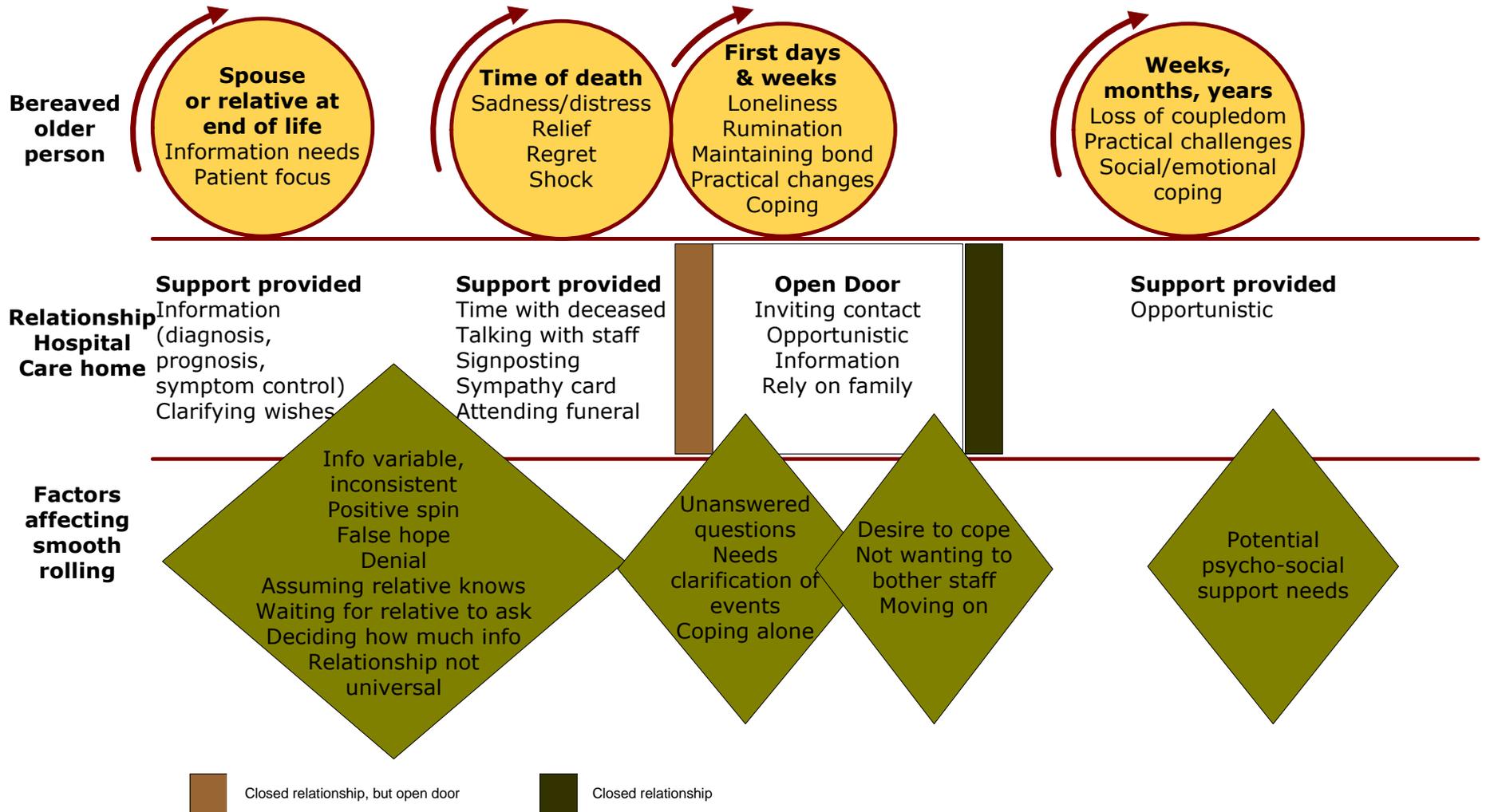
5.4 Bereavement care supports the progression of the Rolling Ball of life

The three preceding themes have built up a picture of bereavement care for older people provided by staff in hospital wards, general practice, community nursing, and care home settings. In essence, the themes map a progression from the time before the death, through the time of the death, and into the days, weeks and months afterwards. At various points along the way healthcare staff are involved with the care and support of the bereaved. The quote below from a GP in a rural practice is used in this fourth theme to describe the idea of bereavement being part of the life journey for an older person.

Bereavement care is probably one of the best instances of what general practice is about. In some ways you always see folks' lives are just, everyone's lives are like a ball just rolling along and every so often your life gets a bit rough around the edges. GP, rural practice

Here the analogy of the Rolling Ball is developed to reflect the experiences of a range of study participants of bereavement, and providing bereavement care. It should be seen as descriptive and noted that there is no intention that it should be used to inform intervention for the bereaved or to indicate when particular aspects of bereavement responses should be felt, or the type of support to provide at any particular time. As the themes described in 5.1 - 5.3 have demonstrated various factors affect the rolling of the ball, with some helping it along while others impede its progress. Figure 12 below demonstrates the engagement of hospital ward or care home staff with bereaved older people. The ball rolls from left to right as the bereavement journey progresses from the pre bereavement stage to a time weeks, months or even years afterwards. The relationship that the relative may have with healthcare staff who cared for their dead spouse or other relative may drive any support provided through the

Figure 12. Keeping the ball rolling - hospital or care home staff



journey. Interactions between staff and bereaved relative, and factors relevant to the effects of bereavement and coping may influence how smoothly the ball runs, or how the relative adapts to bereavement.

The relative's journey faces a particularly challenging episode when the spouse or other relative's life journey is ending or has ended. Before the death, as presented in 5.2, the needs of the relative are informational and concerned with the medical condition, care and comfort of the ill spouse or relative. Staff interact intensely with relatives at this time, and at the time of death the established relationship enables care and support. Relatives' reactions at this time are diverse and depend on the level of information they have been given, and influences like maintaining hope, and denying reality. Their needs are mainly for emotional support in this early stage and people experience sadness and distress, shock, and for some relief or regret. People also need information about arrangements that are necessary after a death, and healthcare staff may engage in explanation of procedures around registering the death, post mortem and funeral planning.

At the time of the death hospital and care home based staff look towards closing their relationship with the relative. As the relative leaves the care of staff within the establishment the 'Open Door' is provided and any further contact is at the relative's instigation. However, the 'Door' that is only slightly ajar effectively closes the relationship. There is only a short time in which it may be acceptable for relatives to reach back in, and for staff to provide further support. After a certain period has passed, as yet undetermined, the 'Door' appears to be more firmly closed and reaching back in is precluded. The relationship can then be considered to be concluded other than for opportunistic meetings.

Staff interviewees, however, maintain awareness that relatives may have support needs later in bereavement. Particular effects experienced are loneliness, ruminating over events that led to the death, maintaining a bond with the dead relative, practical and coping challenges. Hospital and home staff are not in a position to support at this stage and maintain a hope that GPs and community nursing staff provide follow up. They also believe that

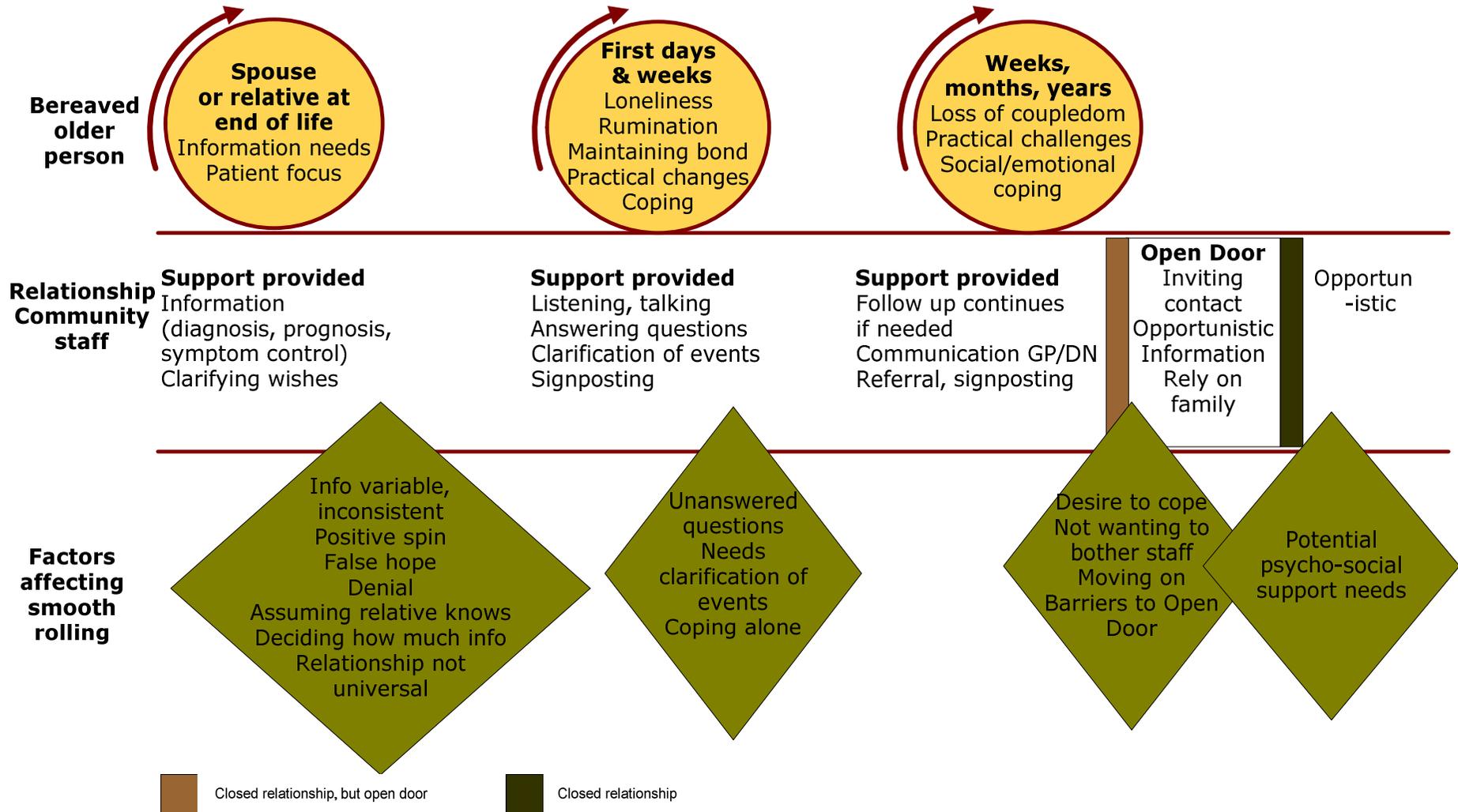
when they have done all that they can to support relatives in the lead up to the death and at the time of the death support needs are minimised and they can safely close the episode of care. Relatives in the study allow this closing down of contact to enable them to keep the ball of their grief journey moving. They find ways to adapt and cope, and use their family and social networks as support and do not look for ongoing support from hospital or care home staff.

Community staff also become involved from the palliative or end stages of the spouse or other relative's illness. There may be less involvement at the time of the death, however, follow up visits may take place to those known and engagement with bereaved older people lasts for a longer period of time after the death than for hospital or care home staff. Interactions at the later stages, after bereavement, allow some discussion of what has happened, and how the relative is coping and adapting. In addition, there is increased opportunity for relatives to ask questions, seek clarification of events that led to the death, and talk in depth about their feelings. A district nurse described the format for a bereavement visit that she would carry out.

I tend to let them sort of speak about how they're feeling. Quite often they want to speak about what happened, because although you know, they can speak about generally how the person was and what was wrong with them to other people, they quite often don't go into all the details of everything that happened. They quite like, often quite like to discuss that so I let them speak and then start asking them how they're feeling and how they're coping through the day, how they're sleeping. I just you know, sort of go from how they're coping through the day, if they're sleeping at night, if they're eating, if they're getting out, if they've got people visiting and I'm not, I don't sit and say it quite like that but these are all the things that I sort of mentally go through.

Figure 13 overleaf illustrates the interactions of community based staff with bereaved older people and traces an older person's journey through the episode of bereavement. Though only subtly different from Figure 12 for hospital and care home staff, the longer time period of involvement with

Figure 13. Keeping the ball rolling - community staff



bereaved older people is demonstrated. This means that the Open Door may be provided at a later time in the bereavement journey.

Bereavement care in the community can be complex and the loss of someone close often adds stress to existing physical and social challenges facing an older person. Fiona's story (Box 3 below) illustrates this complexity. She is a district nurse working in a rural area. She described caring for an older widow for a prolonged period after the loss of her husband. Fiona described the widow's loss of her husband, who was also her main carer, as being particularly difficult. The smooth rolling of her life was compromised and Fiona was challenged to help her to adapt. The widow expressed anger at the loss through dissatisfaction with her husband's care and rebelling against care staff. Fiona visited to attend to her physical needs, however, during visits opportunities were developed for the widow to speak about her husband and bereavement. Different coping strategies were explored though she was reluctant to make changes that would mean losing the bond to her former life. There never was a time when the complexities dissipated though the episode of care came to an end when the widow was admitted to a care home.

Box 3. Fiona's story

One bereaved lady I visited had been very dependent on her husband and really, well after the death struggled to be at home without him. She had almost a bit of anger about her that he had died. It wasn't sudden but from the diagnosis to death it was quite a short time. I think that in a way she feels that things could have been done better. She felt that he'd maybe gone into hospital and they hadn't maybe acted quickly enough to save him you know. She was actually being very awkward and I think what was at the root of it was this deep sadness at being left, but she wouldn't really verbally admit that that was the problem. She wasn't very able physically you know, and there were carers going in but she was really quite demanding of them. Her husband had been a very caring person and she was used to quite a high standard of care. When you actually spoke with her it was this loss that caused her to behave in

this way. There's a befriender service in (town) but she wouldn't accept, said that wasn't what she needed at that particular point.

She'd had to give her dog away because she wasn't able to look after it and this again caused her great animosity. Against all advice she got herself a puppy which really didn't work out very well. She just wanted company but she wasn't able to look after herself let alone a puppy. It actually caused her more problems because you know, it was getting in amongst her feet. She wouldn't say it was the dog that caused her to have the fall, but she had a fall and the dog was around. She ended up being admitted to hospital. At that point we tried to persuade her to go into long term care but really a great reluctance to come out of the home that she'd shared with her husband. She kept saying 'if (husband) had been here,' but there wasn't really anything that anyone could do to change the fact that he wasn't there.

We weren't in specifically because of her bereavement. She'd quite bad circulation in her feet so she needed attention for her legs and she was also on (medication). We did speak about her husband while we were in. She wouldn't open up to everybody, but I had known her for quite a number of years because I had looked after her mother. She'd almost put up like a denial sometimes you know, that she was feeling low in mood but she did open up to me on quite a few occasions. She had a lovely photograph of her husband sitting, and if you turned your attention to it and said, 'oh gosh, that was a lovely photograph,' you know she would open up and say how much she missed him. She described it as just a black hole inside her, just this great sadness that he wasn't around any longer. She never admitted to wanting to be away herself but sometimes she would take to her bed and just refuse to get up. It's not that she couldn't manage, it's just she didn't want to be facing life on her own I suppose. She has actually gone into a residential home now and she seems more settled.

In section 5.3 the need for community staff to interact with their patients who wish to talk about their bereavement after a long period of time has elapsed was highlighted. When some time has passed it may be that difficulties are more complex and, for some, the journey could be said to be impeded in some way. However, some older people in the study also had less need to progress and adapted through living with their memories. Ian, a GP in a city centre practice described interacting with a bereaved older woman whose grandson had taken his own life and her grief was problematic for her (Box 4 below). He described how the sudden loss in this way had affected the bereaved grandmother and caused her to question whether she could have done anything to prevent it. She felt a responsibility to help her family to maintain cohesive relationships and the suicide had changed her understanding of the family dynamics. The GP created an environment where the woman could feel safe to talk about the issues that affected her and he provided support that allowed her to understand her feelings and look forward. The discussions focused on how the grandmother could accept the death and function as a support to others in the family.

Box 4. Ian's story

I had a lady in not that long ago whose grandson had committed suicide and it really had affected her quite badly and she was very upset about it and we just sat and we just spoke. We did this over the space of two or three months and then gradually she just started. She actually, eventually after about two or three months we decided that she would have antidepressants for a while.

It wasn't necessarily about the grandson, what he had done and what he had achieved and all the rest of it. It was more about well where are we now without him and what's happened and the affect of what's happened on the family. 'The family's completely changed,' and I said 'well has the family really completely changed? It's just how we feel about it.' Well, we took that fairly slowly and it took her a while to sort of see a different way of looking at it and then moving on, and about other members of the family

needing her. She just felt that, I think she felt that she failed in some way, you know her family wasn't, wasn't in such a way that everybody was OK and everybody was happy, that actually her family was not like that and in fact one of her grandchildren had committed suicide. I think she was just devastated by that because I think she felt a responsibility to make sure that her family were alright because she was the grandmother. It took her a while to come around to changing the way she thought about it, that maybe it wasn't her responsibility to do that and that there was nothing she could do because she wasn't with everybody all the time. She gradually came to accept it, in fact she was in not long ago and she was a lot better. She's off the antidepressants now and she seems to be getting on with things again.

The Rolling Ball has allowed the description of bereavement and bereavement care from the varied perspectives of participants in the study. Along with the three other themes it was developed to inform the guidelines for bereavement care as a standard for good practice. The themes allowed the identification of a number of items that could be developed as recommendations. These include creating a supportive relationship; identification of needs; facilitating communication between services; organisation of follow up support. The next chapter describes how these were taken forward and included in the draft guidelines along with other factors identified in the literature review, and existing bereavement and end-of-life care literature.

CHAPTER 6

DEVELOPMENT OF THE GUIDELINES FOR BEREAVEMENT CARE

Constantly working with the interview data during the period of analysis led to a stage where development of the guidelines for bereavement care could begin. The four major themes were used as a structure for the guidelines and to identify key recommendations and criteria. This chapter describes the development process and uses selected criteria that were particularly interesting or challenging to illustrate the process. The chapter concludes by describing the consultation that took place to validate the guidelines. Consideration of feedback led to amendment and finalisation of a version for use in practice.

Guidelines are routinely available in healthcare settings in the UK to assist decision making and judgment on a wide range of healthcare topics. They are designed to improve patient outcomes (Bowker et al 2008), reduce costs and inappropriate use of resources, and eliminate unnecessary intervention (Field and Lohr 1992). Guidelines can also be catalysts to practitioners questioning what they do, and learning more about a particular topic (Bowker et al 2008). Development of practice guidelines generally takes place where the topic reflects a clinically important area (SIGN 2008). Currently ageing and quality of life is an important area of research for CSO (2010), and variability in practice, and developing primary or community care are relevant for SIGN (2010).

The development of guidelines generally follows a process of identifying the scope and purpose, listening to the voice of stakeholders, using rigorous methods to develop recommendations, clear presentation, and ensuring applicability to the practice areas of concern. These are aspects of the Appraisal of Guidelines for Research and Evaluation in Europe (AGREE) tool that is used by bodies like SIGN to identify good quality guidelines and to map out the development process (SIGN 2008). Below the development of the guidelines for bereavement care for older people is mapped using AGREE.

6.1 Scope and purpose

The scope of the guidelines for bereavement care for older people has been determined in the preceding chapters by identifying the practice settings, healthcare staff, and the population group for whom the guidelines are relevant. The themes developed from exploration of bereavement care for older people in the practice settings fed into the development of the guidelines. Additionally, participants identified gaps, uncertainties and variability, and made suggestions for criteria for the guidelines. The scope was further defined by specification of the proposed outcomes for the guidelines, some of which were informed by existing literature:

1. For bereaved older people

- They are cared for consistently whatever the circumstances or care setting;
- Their support needs are identified and addressed appropriately (Parkes and Prigerson 2010, Relf 2008);
- Care received is experienced as compassionate and supportive;
- Where there are follow up needs, links with services that can provide support are established (Cobb 2008);
- They are supported to be independent (Beswick et al 2010);
- They receive appropriate information that allows them to seek help (Cobb 2008).

2. For healthcare staff

- Enables a consistent approach across settings to providing bereavement care;
- Enables staff to respond flexibly to the diverse range of needs of bereaved individuals (Carr 2008);
- Allows staff to be confident in their interactions with bereaved older people;
- Allows staff to consider how they currently interact with bereaved older people, and how they may develop their practice;
- Acts as a staff training tool (Stephen et al 2009).

6.2 The voice of stakeholders

Patient or public representation groups often identify inadequate community involvement in planned changes in health services (National Voices 2010). In this study, however, the voices of stakeholders including staff in the practice areas and bereaved older people were key to developing guidelines that were appropriate and relevant (SIGN 2008). The range of views and experiences of participants were used to shape practice recommendations and criteria, and relevant quotations from interviews were included to demonstrate origin of criteria in the guidelines. The participants in the study, as stakeholders, were again included in the consultation process to give feedback on the contents (Bowker et al 2008).

6.3 Methods

When a clinical care process or procedure is the subject of interest, development of guidelines relies on systematically reviewing the evidence from clinical research studies. The results of amalgamation of studies can then be used to determine best practice (SIGN 2008; NICE 2009). However, in the case of bereavement care for older people little evidence exists in the form of intervention studies. Development of the guidelines was therefore based on establishing current practice and gaining consensus through the consultation process (NICE 2009). Analysis of the interview data was used to structure the guidelines and identify criteria that reflect current practice in bereavement care. Quotations from interviewees relevant to criteria in the draft guidelines were included to provide validation of the development process. In addition, research literature on bereavement and bereavement care was drawn on for suitable criteria and to provide additional validation. Pockets of evidence from research in palliative care (Payne 2008), intensive care units (Williams et al 2003, Peters and Lewin 1994), and accident and emergency departments (Williams et al 2000) provided useful criteria. The theoretical literature also provided criteria, for example, as regards assessment of the bereaved (Relf 2008). In addition, existing policy documents were valuable resources, for example, the DOH document 'When a Patient Dies' (DOH 2005); and NICE palliative care guidelines

that include a section on care of the bereaved (NICE 2004). Sources are referenced in the recommendations where applicable.

6.4 Presentation

The intention was to develop a document that was formatted in a way that was familiar to healthcare staff who would be consulted on its suitability and feasibility in practice. Reference was made to the layout of NHS QIS guidelines (NHS QIS 2010); SIGN guidelines (SIGN 2009); and JBI evidence based practice series (JBI 2003). NHS QIS provided the most useful format that was believed to be easy to follow and provided a framework for logical progression through the guidelines. The layout of recommendations in particular, was informed by the NHS QIS format.

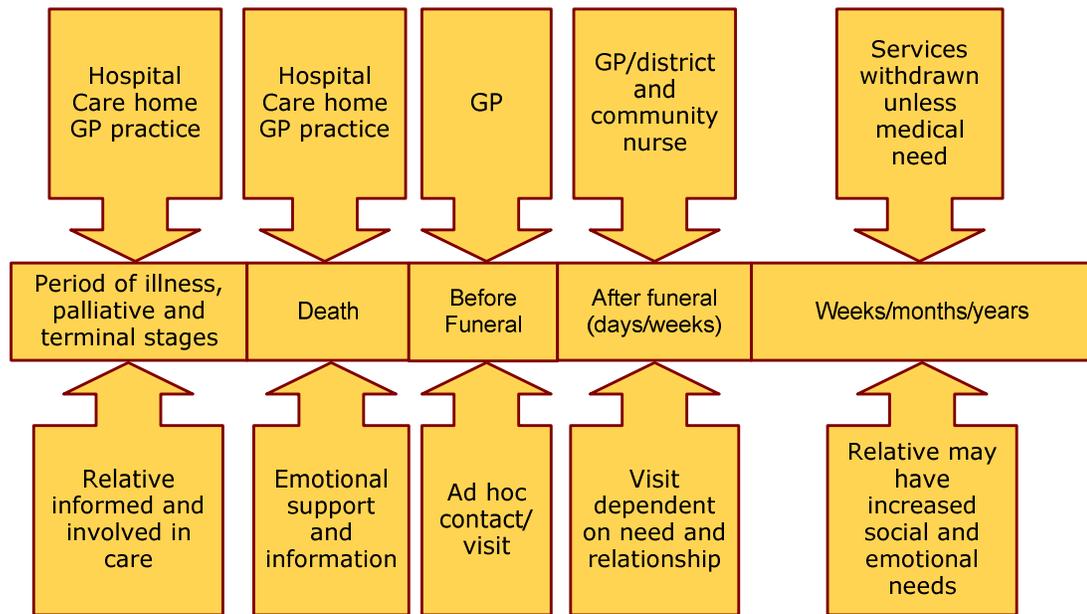
The drafted guidelines for bereavement care for older people contained two main sections:

Part A. Development of the guidelines;

Part B. Draft guidelines for bereavement care for older people.

Part A included an introductory section that highlighted the impact of bereavement in the population and the consequent burden it may place on healthcare services. The effects of bereavement on older people were commented on, and the variable nature of bereavement care provided in healthcare settings was identified. The introduction went on to explore bereavement for older people through summarising findings of the literature review and key themes from the interview study. Bereavement care was presented using a timeline that arose from through early interview analysis (Figure 14 below). The reader was then provided with an explanation of the layout of the guidelines, and intended outcomes from their use were identified. In Part B recommendation statements were developed. Their presentation was structured by the timeline with three sections relating to pre-bereavement preparation; care at the time of the death; and follow up for bereaved older people. Each recommendation was given a title, and contained an explanatory statement, the rationale and a list of criteria. Criteria are focused on actions and

Figure 14. Timeline for bereavement care



give direct instructions, and where relevant they emphasise the involvement of the bereaved older person, for example, use of the words 'offer' and 'discuss' (NICE 2009).

The interview study revealed a lack of resources and information for staff to draw on for their own use, and for directing the bereaved to services that may provide additional support. Bereaved older people in the study also indicated that they did not know what support services were available. The final section of the guidelines lists resources for bereaved older people and for healthcare staff:

- bereavement support organisations;
- bereavement support information;
- social support services;
- organisations for older people;
- information for healthcare staff.

SIGN guidelines are usually accompanied by a quick reference guide that provides a summary of the key recommendations and other information from the

guidelines. Contents reflect the recommendations and criteria that potentially have the highest impact for service users (SIGN 2008). A shortened version of the bereavement care guidelines was produced for the quick reference of staff in a ward, care home, general practice or community nursing team. The draft guidelines were printed professionally with specially designed card covers, and the short version printed on card in a double folded leaflet format.

6.5 Consultation on the guidelines

After completion of a draft version, guidelines enter a validation phase where key stakeholders and experts in the field are consulted and asked to provide commentary (SIGN 2008, NICE 2009). Typical issues on which feedback is received are general positive or negative views; omissions; the applicability of the guidelines in practice; wording; potential resource implications (NICE 2009). Consultation on the draft bereavement care guidelines took place with study participants initially, and also with others who had an interest in the topic area or had input to bereavement care in their roles. Key aims of the consultation on the guidelines for bereavement care for older people were:

- to explore initial impressions of the guidelines;
- look critically at the contents and format of the guidelines;
- draw consensus on the value of criteria;
- gather suggestions for improvement;
- examine how the documents could be used, and how to introduce them to practice.

6.6 Key issues in developing the guidelines

Through the development of the draft guidelines a number of key issues arose that needed careful consideration and reviewing of research literature to identify appropriate criteria. Five examples below illustrate the process of developing the guidelines.

6.6.1 Pre bereavement sharing of information with the relative

Provision of information before the death is a key role of healthcare staff to help family members anticipate the loss of a relative. There are many opportunities for giving information and staff are concerned to give the appropriate information in the appropriate amount. At this intensely emotional time staff may hold back from giving information as they are aware that the relative may not take in what is said, or they fear overburdening the person. Relatives also differ and some want as much information as possible while others are more willing to let events take place without being party to too much detail, for example, about the ill person's diagnosis and prognosis. The guidelines needed to indicate relevant information provision and appropriate delivery, and to reduce variability in practice.

The literature indicates that interaction with medical staff in the pre bereavement phase may lead to less depression in relatives and carers (Kutner and Kilbourne 2009; Schaefer and Block 2009). Early discussion about diagnosis and prognosis, even if it is short, is desired by most relatives to enable emotional and practical preparation for the death. In addition, provision of written information about bereavement as a component of a bereavement intervention in an intensive care unit has been found to reduce long term bereavement difficulties (Lautrette et al 2007). Discussion of withdrawal of life saving treatment may not, however, be welcomed (Schaefer and Block 2009). The recommendation criteria were developed to reflect the type of information that relatives may need. In addition, it is suggested that the process of imparting the information is informed by knowledge of the person and what they may require (see Figure 15 overleaf).

6.6.2 Assessment

Identification of bereaved older people who may be at risk of experiencing complicated grief was a key concern of staff interviewees. Previous research on risk factors and risk assessment was consulted (Minton and Barron 2008). However, risk assessments are complex and interviews in this study revealed lack of understanding in healthcare staff of the risk factors that may lead to an older

Figure 15. Information provision (extracted from draft guidelines)

Criteria
Help the older person to understand that their spouse/partner or relative is dying
Give the relative(s) information that they can cope with: <ul style="list-style-type: none">➤ prognosis➤ time scale➤ care decisions➤ what the death could be like➤ what to expect in bereavement
Frequently reiterate the information
Include the family in decisions about end of life care
Involve the family in the care of the dying person
Maintain a high standard of care for the dying person
Give the family the opportunity to plan ahead for the time of the death and make their wishes known

person developing complicated grieving. A key issue to address in the guidelines was, therefore, to develop a means of identification of those at risk that led to appropriate follow up planning. A GP taking part in the study suggested that:

There must be a series of three or four brief questions that can elicit the crucial information. I'm thinking of the example of something like the CAGE questionnaire to identify alcohol problems.

Bereavement follow up services, however, are lacking and there is an ethical dilemma that questions whether risk assessment should be carried out if no intervention is available. An acceptable outcome may be notification of the bereaved relative's GP when risk factors are identified. However, it may be that a bereaved older person with identified risk factors needs no intervention, while someone with no apparent risk factors is the person who needs support. Knowledge of the person is again needed to judge whether or not to communicate concerns.

Healthcare staff may have an opportunity to assess risk of poor bereavement outcome in the older person in the time before the death of the patient. This can be developed within the relationship built up with the family through caring for the patient. Assessment could also take place at the time of the death, in the weeks and months after, or on repeated occasions through the bereavement journey to gauge progress. For the guidelines a simple list of assessment criteria was required. Factors included are situational (circumstances of the death; concurrent life events), personal (relationship to the deceased; pre existing health) and environmental (social support) (Relf 2008, Worden 2001) (Figure 16).

Figure 16. Risk factor identification (extracted from draft guidelines)

Assessment criteria	Risk factors
Relationship to deceased	Spouse/partner, parent, adult child, grand parent, sibling, carer, cared for
Circumstances of the death	Sudden, young person, trauma, suicide
Family/friends/community support	None identified, or unreliable
Health	Poor physical health, previous mental health problems
Other bereavement(s), last 2 years	1 or more, relationship as above
Perceived support needs	Relative's stated needs

A documentation tool was developed and included in the draft guidelines, and it was anticipated that the consultation process would help to clarify whether it was feasible or appropriate for use in practice. Measurement in terms of a scale was not believed to be helpful if there was no provision of a variety of bereavement care interventions that could address a range of difficulties.

6.6.3 Expressing words of sympathy

Staff interviewees, particularly untrained nurses and care staff, expressed a need for guidance on appropriate things to say to the bereaved. They feared upsetting people and appearing uncaring. The lack of training on death, dying and

bereavement was identified as contributing to reduced confidence in interacting appropriately with the bereaved. Interviewees in the study variously suggested things that they might say that they believe are empathetic and comforting (Figure 17).

Figure 17. Expressing words of sympathy (extracted from draft guidelines)

Criteria
Express words of sympathy
➤ 'I am very sorry'
➤ 'this must be very painful for you'
➤ 'you will miss him/her terribly'
➤ 'you will have some lovely memories of him/her'
➤ 'it was a privilege to look after him/her'
➤ 'he/she will not be in pain any more'
Allow the bereaved to express their feelings and acknowledge them, saying that 'it is alright to feel that way'
Provide time for the bereaved person to talk with a nurse or doctor who knew the person who died about their feelings; the person who died; and what the loss means to them
Give explanations: illness, events at death, care provided
Reassure the relative that they did all they could
Answer questions and listen to concerns
Touch the bereaved person
Don't be afraid to show your own emotions

Particular phrases included were anticipated to be controversial by assuming too much about the relationship between the bereaved and the deceased, for example, 'you will miss him/her terribly.' More empathetic responses that use open questions to allow the bereaved to explore their grief may be more appropriate (Raphael 1984), and were also included in the criteria. Further criteria that may raise questions concerned touching the bereaved relative, and

staff members showing emotion. Criteria were included though amendment was anticipated to be necessary at a later stage.

6.6.4 Facilitating ongoing support

When asked during interviews to talk about communication with other services about bereaved relatives most staff had little to say. Little need for such discussion was identified, and few had considered it as a possibility. Communication between hospital or care home, and the general practice only took place on the level of passing on information about the death. In addition, there was poor awareness of whether or not this led to bereavement follow up for the relatives. The guidelines, therefore, could be used to develop such communication links.

A particular example of when communication may be necessary could be when risk factors are identified and a staff member knows the relative well enough to consider that they may face difficulties in coping with bereavement. The relative, however, is not regarded as being a patient and staff may be concerned about maintaining confidentiality. This indicates that it would be necessary to obtain consent before contacting another service. In the guidelines the GP, district nursing team, and social work department were identified as appropriate communication links (Williams et al 2000, NHS Grampian 2005) (Figure 18).

Figure 18. Communication links (extracted from draft guidelines)

<p>Criteria</p> <p>With the bereaved older person's consent, communicate concerns based on risk factor assessment and judgment of the person's coping abilities to other healthcare professionals on the day of the death:</p> <ul style="list-style-type: none">➤ GP➤ district nursing team➤ social work department (if the older person has immediate care/accommodation needs)
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GPs in the study described a process of notification of practice staff about the death of a patient. This is in place to bring the death to the attention of members of staff who knew the patient and may be aware of follow up needs of the relatives. There were, however, difficulties with the procedure when the family was unknown to any staff or were patients of another practice. Bereaved relatives in these circumstances generally receive no bereavement support from community healthcare staff. Included criteria indicate a chain of communication from reception staff, who receive notification of the death, to clinical staff. In circumstances where the relative has had no healthcare contacts prior to the death, the responsibility for follow up falls to the GP with whom the dead relative was registered (Figure 19).

Figure 19. Cascade of information in GP practice (extracted from draft guidelines)

Criteria
Death notification received from the hospital
➤ Receptionist notifies all GPs and DNs of the death
➤ GP who knows family to make contact with the closest family member – visit in first 3 days (before funeral)/phone if not in/send sympathy card or letter if unable to contact
➤ If DN or community nurses know the family – phone in first 3 days, home visit in first 2-6 weeks (after funeral)
➤ GP/nurse notifies receptionist if planning to visit
➤ If no member of staff responds to initial communication, receptionist notifies GP whom deceased/family registered with, who may then visit
➤ Note the bereavement in the medical records of the bereaved older person

Ongoing support can also take the form of the relative reaching back into services for clarification of events that led to the death, or information about necessary practical arrangements following the death (Parkes 1998). Criteria were added that facilitate the 'Open Door' (Figure 20 below).

Figure 20. Reach back into services (extracted from draft guidelines)

Criteria
Invite the bereaved older person to contact the ward, home or general practice if they have questions about the death, about practical arrangements, or to discuss other concerns
Provide contact details for the ward, care home, or general practice. Give the name of someone who knows the family and was present at the death.
Inform the relative that if they want to meet with staff at a later date to discuss the death, that this can be arranged

6.6.5 Follow up from non community staff

The barrier identified previously as regards the ability of non community based services to follow up bereaved relatives was a clear difficulty when the major gap identified was in providing support in the weeks, months and years post bereavement. A nurse in a care home expressed frustration at not being able to follow up:

They need just somebody to see if they are OK and if they're coping, but I don't know who would do that. In this setting I don't think we could really do it because, well the only time I've done it has been in my own time because I've just built up that relationship. Senior nurse, care home

Community staff interviewed for the study consistently reported carrying out follow up of bereaved older people known to them. However, follow up from hospital and care home based staff was low level in comparison. There was some communication in sympathy cards, letters, or by attending funerals but little to address bereavement experiences of relatives. The guidelines provide an opportunity to develop activities that could feasibly take place and be seen as supportive by relatives.

Follow up from non community based staff, the care home manager in particular, in terms of one or more bereavement visits may be possible. Staff interviewees routinely described the care home as the resident's home where family and friends are welcomed. Relationships and strong bonds are built, some over a

number of years. However, the death of the resident and attendance at the funeral appear to signal the end of the relationship. Opportunity has been developed in the guidelines for care home managers or trained nurses to be involved in follow up visits to bereaved older people. Previous research findings indicate that bereaved relatives favour a meeting with a member of staff who knew the deceased and the family well and this is built into criteria (Milberg et al 2008) (Figure 21).

Figure 21. Follow up from non community staff (extracted from draft guidelines)

Criteria
Follow up phone call to relatives 1-2 days after the death
➤ allow time for the call
➤ ask how the relative is feeling
➤ ask whether they have any questions about the death
➤ find out how the family are coping
➤ find out how the funeral arrangements are progressing
➤ ask whether they have any other concerns
➤ don't be afraid to mention the dead person by name
➤ notify GP of any concerns raised that hospital/home staff can't address (with the bereaved older person's permission)
Send a sympathy card
Provide contact details for the ward or home, and a named person who knew the family well and can answer questions about the death
Invite relatives to contact the ward or home by phone or to visit in person if they have further support needs
If required, arrange a follow up meeting for the bereaved older person with a member of staff who knew the patient and family
If appropriate, attend the funeral to represent the ward or home and to show ongoing care for the person and their family

6.7 Consultation on the guidelines

Copies of the draft guidelines were sent out to healthcare staff taking part in the study with an invitation to take part in one of three focus group discussions.

Twenty seven study participants based in close proximity to the university where the focus group meetings were scheduled to take place were included in this initial mailing. Response was slow and only five invitees indicated willingness to attend a focus group. A reminder letter was sent out ten days ahead of the meetings. This provoked additional responses by telephone or email, though none for focus group participation. Pressure of workload was the usual reason given for being unable to attend, some staff had moved to different jobs and locations, and one ward had been closed. In total three participants took part in one focus group meeting. They were a district nurse, a deputy manager of a care home, and a hospital chaplain. One potential participant could not attend the same meeting as the others, and the remaining participant was ill on the day and unable to attend.

Staff participants based in rural locations were contacted by phone via managers or recruitment facilitators at the study centres. They were informed about the output of the research and asked how it would be best to obtain their feedback. At most centres it was agreed that they would be contacted again in 2-3 weeks, after the guidelines had been sent out, to arrange a feedback meeting. However, feedback was only successfully obtained from participants at one community hospital, and at the rural general practice taking part in the study. Up to three attempts to contact study centres were made and often the lead person was unavailable and did not return calls. In the community hospitals staff sickness was a problem with increased pressure on time meaning people were unable to re-engage with the study.

Bereaved older people who had participated in an interview and lived close to the university were also sent copies of the guidelines and invited to a focus group to provide feedback. However, none of the four initially contacted responded to the invitation. One participant's son made contact and requested that his parent be withdrawn from the consultation as receiving the mailing had caused unnecessary distress. No other reasons for non participation were provided. An alternative procedure was used to invite feedback from the remaining two participants who

lived rurally. They were contacted by letter and asked if they would be willing to read and comment on the guidelines. This resulted in one relative providing feedback in a meeting that took place at his home.

Other contacts with an interest in the project or in bereavement generally were also invited to provide feedback on the guidelines. These included members of the advisory group for the project who provided feedback separately at meetings, by phone, and by email. Four GBRIG members who were a specialist nurse, a district nurse, a member of clinical governance staff, and a psychiatrist (also a member of the advisory group) provided feedback. The hospital specialist nurses group gave oral feedback when the documents were presented at a meeting, and one member (also a member of GBRIG) gave a separate response. The community Macmillan nurses who had been an original target group for feedback were not approached because they had already withdrawn from facilitating the study at the recruitment stage. Staff shortage and lack of time were given as reasons for non participation. Additional contacts who provided feedback in person, by email or by phone were: a mental health researcher; a bereavement researcher; a lecturer in nursing; a hospital chaplain; a community nurse; a consultant geriatrician; and a hospice nurse.

Members of the CHAIN bereavement and loss forum were approached and invited to take part in the consultation via the CHAIN email network. A link to the guidelines on the university website was circulated along with a link to the online questionnaire (Appendix 11). This produced twelve responses in the five weeks that were given for participation. Nine participants gave information about their roles. They were employed clinically in a variety of fields including: old age psychiatry; inter-professional education; clinical psychology; a GP (Macmillan); mental health first aid; occupational therapy (Macmillan); community nursing; and nurse education.

6.8 Contents of feedback

Feedback from the consultation was recorded in a spreadsheet along with notes regarding the decision making process that fed into development of a finalised version (Appendix 12). General impressions are provided below, followed by commentary on key points in the feedback that were developed to amend and finalise the guidelines. Many respondents suggested wording alterations, eliminating technical language, and made comment on the literature review. These were considered while developing the finalised version of the guidelines though are not discussed further here.

In general, feedback on the draft guidelines was positive and participants thought that there had been considered thought in its development and that it would be a useful addition to healthcare practice. Respondents said that the guidelines provided direction for healthcare staff when interacting with bereaved older people. It was seen to provide evidence for healthcare providers to maintain a link with bereaved older people through follow up. In addition, respondents believed that it addressed the needs of a variety of disciplines as regards care they can provide and that it promotes consistent care. Benefits for older people were identified when bereavement care is not left to chance as it has been in the past. By receiving appropriate support in bereavement it was felt that people would be physically and mentally stronger and more able to cope with their new situation. A participant said that the guidelines could act as an *aide memoir* to things that should be discussed with the bereaved and though they would not remember everything they would '*remember the carefully enquiring tone and concern in raising issues.*' Additionally, a district nurse and a ward sister in a community hospital indicated that they would use the guidelines to identify criteria that could enhance bereavement care already provided. This is how, throughout the development of the guidelines, it was envisaged that it could be accessed. However, testing the efficacy and cost effectiveness of using the guidelines, it was suggested, would be crucial to determining whether it would make a difference to the bereaved.

It was generally thought that the guidelines usefully raise awareness of the affects of bereavement on an older person. A specialist nurse initially wondered why it was focused on older people, but she said that on reading through she had decided that it was important that the effects of bereavement on older people are highlighted. The potential of using the guidelines as a training tool for healthcare staff was also identified, and respondents believed that it would enable the development of bereavement care skills and practices. A GP respondent thought that the guidelines would be an ideal topic for a practice learning session, as a means of *'consolidating the approach to bereavement care, and ensuring people don't slip through the net.'*

Providing a contrasting view, a ward sister believed that the use of the guidelines was outside the scope of hospital staff, and that it may be more relevant for community and care home staff. She said that she spoke for other members of her team whose views she had sought through discussion at a meeting. Her negative opinion may be as a result of her experience that relatives are not usually with the patients when they die. She did, however, think that support for relatives was an important aspect of end of life care though the focus was on the patient. She also thought that the guidelines would add a lot to workload as regards end of life care. By following the guidelines she believed that she would be caring for *'half the city.'* She therefore dismissed criteria in the guidelines that are not currently part of care provision. For example, she said that staff would not be involved with discussing what bereavement may be like with the relative. The only part of the guidelines that was of interest was the resource list and for this reason she suggested that the short version of the guidelines could be given to relatives with other printed information. In addition, she thought that the quotations from interviewees were inappropriate and lowered the tone of the guidelines.

6.9 The finalisation process

The guidelines were amended, new criteria added and criteria believed to be unhelpful were removed. This followed a process of additional thought and

researching of issues raised in the consultation. Some suggested changes were included in the finalised guidelines, and others were rejected. All were recorded in the spreadsheet developed for the purpose (Appendix 12). Issues raised in feedback and changes made to Parts A and B of the guidelines are reported below.

6.9.1 Part A

Part A, the introductory section of the guidelines, was generally thought to be useful, in an accessible format, and informative. A respondent said that it '*was well presented, well pitched, and a useful resource for training.*' Other respondents, however, questioned whether an introductory section in such detail was necessary in practice guidelines. In addition, it was suggested that the list of recommendations should be at the front as this may be the only thing some read. After careful consideration in the process of finalisation the introductory section was updated and retained in the full guidelines rather than being removed or included as an appendix to the recommendations. By retaining Part A and focusing attention on bereavement and older people their needs are highlighted and awareness of the impact of bereavement is raised.

The timeline for bereavement care presented in Part A was generally regarded as a useful interpretation of bereavement care provision. However, a district nurse felt that it did not fully reflect her input with relatives. She thought community nursing should be represented at the pre bereavement stage and as supporters of the bereaved throughout their bereavement journey. In addition, her experience is that there is much more collaboration between staff with different roles than the diagram suggests. The timeline represented fragmentation of services when it should reflect more overlap. In addition, the timeline may reflect a stages of grief model of bereavement and be interpreted as a guide to intervention. This was not the intention and the timeline was removed in the finalised version. For the same reason the 'Rolling Ball' diagrams were also not included in the finalised version though they may reflect more accurately the roles of the range of healthcare staff. The 'Rolling Ball' was also believed to be complex and not

practically useful in the guidelines. To reflect the completed analysis and interpretation of the interview data summarised versions of the first three themes replace the early findings represented in the draft guidelines.

Throughout the consultation little comment was made on the intended outcomes from using the guidelines. However, use of the word 'confident' in the statement 'allows staff to be confident in their interactions with bereaved older people' was queried by a district nurse. Her experience was that caring for bereaved relatives evokes anxiety in nurses and though they believe that everything they say may be right, they are aware that people interpret things differently. She suggested 'more self aware' as an alternative term. However, this lacks clarity and because increased confidence in interacting with bereaved older people was believed to be a common need for staff no amendment was made to the original statement.

6.9.2 Part B

CHAIN respondents were asked to rate recommendations in Part B in terms of their opinions about appropriateness for use in practice. All said that the separate recommendations were either 'very appropriate' or 'partially appropriate', with most recording 'very appropriate'. The recommendations on facilitating ongoing support, and follow up from non community based staff each recorded three responses of partially appropriate. These reflect areas that may require developments to current practice and may have raised concerns about feasibility. There were no comments provided that explained reasons for answering 'partially appropriate.' Respondents across the consultation generally liked the use of quotations from interviewees to back up criteria.

Discussion with the widower who took part in the consultation process provided further validation of some of the recommendations and criteria included. Particular recommendations about providing relatives with information about the ill person's diagnosis and prognosis were endorsed. However, it was recognised that some may be unable to cope with the information and that staff needed to discern who and at what level it was appropriate to inform. He also endorsed

how helpful it was for him that staff made efforts to allow the family to stay in the hospital ward in the lead up to his wife's death. This is reflected in the guidelines in terms of creating a supportive environment.

Post bereavement, the widower believed that having an opportunity to verbalise concerns would be helpful, and he thought that a bereavement follow up visit would provide the opportunity. He was also in favour of being provided with an appointment for a follow up meeting or phone call with the consultant or other member of staff who knew the circumstances of the death. This would enable clarification of events, and finding answers to questions, particularly '*what ifs?*' However, he warned that when asked how they are coping, bereaved older people are likely to be ashamed to say they are not coping and may only give hints. This was also said by a focus group member who, through experience of working with older people, identified resistance to accepting offers of support. The guidelines were believed, however, to provide sufficient opportunities to explore a relative's emotional and practical coping. No further amendments were made to encourage further probing that may be intrusive.

During the consultation on the guidelines a number of issues arose from Part B that were particularly challenging and needed further consideration. These are described below with discussion of how they were addressed in the finalised version.

Ideal versus achievable criteria

The guidelines were questioned in terms of proposing criteria that may be ideals rather than immediately achievable in the context of current healthcare delivery. Some respondents agreed with Bowker et al (2008) that recommendations seen as aspirational should be avoided when there was poor capacity for them to become reality. However, some criteria were seen as examples of best practice that staff could work towards achieving. For example, criteria in terms of bereavement follow up planning (Figure 22 overleaf) were seen as challenging and respondents were unsure whether the suggested timing of contacts was

Figure 22. Visiting plan (extracted from draft guidelines)

Criteria

Below is an example of a visit plan that can be used for an older person:

- Visit before funeral – GP/care home manager
- 2-6 weeks after funeral – DN or community nurse (if relative known)/care home manager
- Further follow up is dependent on need
- Arrange phone contact after 3 months, if the person is in agreement, when there are more likely to be support needs – GP/DN/community nurse/care home manager

achievable. A further ideal set out in the guidelines was for the input of non community based staff as regards follow up of bereaved older people (Figure 21, p 190). This was thought to be helpful, though in reality money drives what can be done and it was believed to be unlikely that care home staff could be paid to visit bereaved relatives. In the finalised version criteria were retained to provide flexibility for home staff who wanted to follow up the bereaved to do so. In addition, a phone call is possible at little extra cost in terms of time and resources. Consensus in the focus group was that challenging criteria should remain as goals for service development and a decision was made to retain best practice ideals.

Assessment

The assessment tool provided in the guidelines (Figure 16, p 185) was believed to be useful for identifying potential bereavement difficulties and notifying community staff. However, there was concern about over reaction and too readily passing on concerns. A district nurse viewed the guidelines as useful within the context of nurses as autonomous practitioners and was confident that knowledge of the family would guide the provision of individualised care. This means that careful thought would be given, while using the guidelines, to interact appropriately with the bereaved older person in their particular situation and only pass on information when necessary. Two further respondents liked the idea of risk factor assessment, but wanted some specific direction about what should be

done with the results. They were in favour of a scoring system that may include items that would score zero indicating no risk and therefore considering resilience along with vulnerability (Relf 2008). There should also be a procedure for notifying the GP if the score exceeded a stated level. It was also thought that the assessment should be repeated on different occasions to measure progress. One respondent thought that an assessment system should be piloted for further clarification of how it could work in practice.

A participating GP further explored capacity to assess in his role. He read the assessment criteria as a mental checklist for healthcare staff to use when interacting with someone who has been bereaved. However, he believed that all bereaved older people closely related to the deceased should be contacted by a member of community staff, regardless of any risk scoring, when additional support needs can be identified. No amendments have been made to the assessment procedure in the guidelines as there does not appear to be capacity in statutory services to carry out detailed assessment. The use of the simple risk factor assessment could lead to better understanding of risk, particularly as regards circumstances of the death, and increased recognition of needs (Worden 2001, Relf 2008). However, communication of concerns may be the only realistic expectation when there is lack of capacity to address complex needs. The documentation tool was removed from the finalised guidelines as feedback indicated that it was impractical as regards storage, and it did not have any useful purpose.

Directive statements

Respondents in the study variously commented on the use of statements that were considered to be directive, for example, 'encourage family members to come together to support each other.' This and some of the suggestions for things to say to a bereaved older person (see Figure 17, p 186) were thought to be patronising and respondents encouraged their removal from the guidelines. One respondent said that,

Open questions could be more helpful. To be empathic, we have to see the world through the other person's eyes, and until we have enquired through open questions, we can't know how to do that. The mistake is to assume they are feeling what we think we would feel. Lecturer

There was also a suggestion that the news of a death may not always be 'bad' and that 'breaking bad news' should be reduced to 'breaking the news.' In the finalised version these comments have been used to make appropriate changes, for example, 'you will miss him/her terribly' has been deleted.

Other comments

A selection of additional comments and suggestions for improvement that arose during the consultation and were no less important are recorded in Table 14 overleaf. The decision making process for finalisation is also recorded along with any amendments.

6.9.3 Short guidelines

Feedback on the short version of the guidelines was also encouraging. However, a respondent was concerned that healthcare staff would read the short version and then not read the full version. In addition, they may not view the short version as containing anything that they did not already know. It was believed that the full version was more substantial and that it should be read by all healthcare staff who have contact with bereaved older people. Other respondents believed that the short version contained a useful summary that would be used regularly. Throughout the consultation respondents reiterated the pressure of a heavy workload in many healthcare settings, and it was often said that staff did not have time to read and engage with all written information that required attention. It was therefore decided that the short version of the bereavement care guidelines should be retained after updating and rechecking to ensure that the key points from the full guidelines were reflected.

Table 14. Additional comments on recommendations

Comment/suggestion	Decision making	Amendment
<p>Providing a definite appointment for the bereaved to meet with a staff member to discuss the death.</p>	<p>Opportunity for relative to find answers to questions and clarify events.</p> <p>Consultant or nurse who knew the patient would be appropriate person to meet.</p> <p>Anticipated difficulties - staff would have to find time; people may not turn up.</p>	<p>Included as a best practice ideal.</p>
<p>Be specific about how much time needed for 'breaking the news'; 'time spent with relatives after the death'</p>	<p>Represents time that staff could reasonably expect to have to find to care for bereaved older people.</p> <p>Anticipated difficulties - that forward planning may not be feasible; length of time may not equate with quality of the contact.</p>	<p>Times of half an hour and an hour respectively are recommended.</p>
<p>Does not reflect needs of older people from non Christian faiths. Religious and/or cultural needs should be explored by staff.</p>	<p>No specific information about needs of non Christian faiths in bereavement is available.</p>	<p>Staff are directed to discuss specific needs with families.</p>
<p>The place of the patient in providing information for the family.</p>	<p>The patient's wishes can determine outcomes for family.</p> <p>Diagnosis, prognosis etc. should be discussed by appropriate person e.g. a GP or district nurse.</p>	<p>Opportunity for dialogue between patient, relative and care staff about the imminent death is developed in a recommendation. The need for the appropriately trained person to deliver the information is emphasised.</p>

Comment/suggestion	Decision making	Amendment
Recognising the value of sitting with someone in silence.	Believed by many bereavement care providers to be supportive for the bereaved.	Criteria added
Should indicate locally available services for the bereaved.	The resource listing should be adapted to reflect services that are available locally.	Capacity provided for local services to be included in listing.
Suggesting when it may be appropriate to seek counselling.	Inappropriate at the time of the death or relatively soon afterwards.	Removed from recommendations in early phases of bereavement i.e. before the death, at the time of the death. Left as a criteria for follow up bereavement care.
Something should be added about support for older people bereaved by suicide.	The guidelines were developed to flexibly respond to diversity of situations of bereaved older people. Not believed necessary to be specific about suicide.	None
The guidelines focused on spousal bereavement with no regard to other relationships.	This is true for the research process that fed into the guidelines, but what was developed was designed to be responsive to diversity. There is no indication in the literature that supportive strategies for bereaved spouses can't be supportive for those with different relationships.	None

Finalised versions of the guidelines were developed using feedback from the consultation process. Amendments were made as suggested by many of the comments received but also guided by the decision making process described above. The finalised versions are included as supplementary documents to this thesis. In the next chapter of the thesis the research process that led to the guidelines for bereavement care will be critically assessed for validity and ability to lead to appropriate recommendations. As well as the guidelines, the results of the exploratory study will be discussed in terms of implications for healthcare practice and the delivery of bereavement care for older people.

CHAPTER 7

DISCUSSION

This chapter of the thesis reviews bereavement care for older people in healthcare settings as it is currently provided and in terms of how it may be enhanced. Discussion and interpretation of the major findings (the themes from the interview analysis) and the outcome (the guidelines for bereavement care) of the study takes place within the context of previous research and theory as well as current policy around bereavement. The implications of the research for healthcare practice are then considered, and the direction of future research determined. The chapter includes an examination of the strengths and limitations of the research methods.

The study included the voice of older people who described experiences of bereavement that, after many months continue to be emotionally difficult. Experiences described illuminated the multi-faceted nature of bereavement and supported evidence that older people face an accumulation of losses that compromise ability to adapt (Parkes and Prigerson 2010, Adriaensen 2006, Hansson and Stroebe 2007). Loss of income, reduced social support, deteriorating health, and social isolation are examples of factors brought up in interviews, all threatening to the older person's independence. Older people, through their grief responses, strive to make meaning and amalgamate losses into their ongoing lives. The study revealed diversity of responses, in particular to bereavement, that were found to reflect those presented in the Dual Process Model (Stroebe and Schut 1999) (Chapter 1). The dynamic process of oscillating between confronting loss orientated and restoration orientated stressors was clearly articulated by participants, along with efforts to take time out of grieving by becoming involved with other activities. Attention to the two stressors, loss and restoration, is seen by Stroebe and Schut (2010) as necessary for adaptive coping.

Diversity of responses to loss indicated that a one size fits all type approach to bereavement care would not be appropriate and that flexibility was key to interactions with the bereaved. Parkes and Prigerson (2010) viewed social support for bereaved older people as a guard against poor health and the

outcome of this project sought to promote social support of older people as a factor that healthcare staff may have input in addressing. Healthcare staff interviewees were aware of the kind of difficulties older people encounter and clearly make efforts to provide support within the constraints of their services. Weaknesses in services and lack of flexibility, however, were apparent and improvements that could be made in the support of older people were identified. Concern about provision of ongoing care for the ageing population require that older people should be self caring and independent for as long as possible (The Scottish Government 2009; page 7). The guidelines presented in this study provide a framework for bereavement care designed to appropriately support older people.

The three practice settings that were included in the study were brought together to fully explore what is currently done for bereaved older people in healthcare services. The settings included are where older people are likely to experience the death of someone close to them and to become bereaved (Office for National Statistics 2009). In addition, this research recognised that older people may have contact with staff in more than one healthcare setting during their bereavement journey. Previously research into bereavement care practice has focused on single healthcare settings, for example Main (2000) in general practice, Lyttle (2001) in community nursing, Walsh et al (2008) in hospitals, and Davidson (2003) in care homes. In this study these key areas are brought together and real or potential contacts with healthcare staff are mapped through the bereavement journey. This recognises an older person's bereavement journey as an ongoing concern from the time leading up to the death that continues beyond the immediate time of the death, and for some for many years.

The four key themes that were developed from interview data collected in the study are discussed below in terms of previous research, theoretical perspectives on bereavement, and current policy development around bereavement and bereavement care. The interpretations reflect particular aspects of bereavement and bereavement care that were important for study participants and for the development of suitable guidelines for healthcare staff to use in practice. However, it seems pertinent to set this within the context

of the research project and to be clear about the strengths and weaknesses of the methods employed. The next section, therefore, reviews the study and will allow assessment of the validity of the findings and outcome.

7.1 Strengths and limitations of the research methodology and methods

Key strengths of the study were the use of phenomenology to reveal experiences of bereavement and provision of bereavement care; inclusion of the voice of a range of healthcare staff; the flexible nature of the interview to allow development of thoughts; qualitative research informing service development; and the strongly positive nature of feedback received to the consultation on the guidelines. Limitations to the validity of the study were recruitment difficulties that restricted the range and number of bereaved older people who took part; the tendency of interviewees, particularly healthcare staff, to generalise; and the low quantity of response to the consultation on the guidelines from study participants. These are explored in more detail below.

Phenomenological methodology

Munhall (1994) described phenomenology as a methodology that allows examination of the intrinsic nature of ordinary human experiences in their social context to discover meaning. Data collection in interviews for the current study gathered a range of subjective experiences that described bereavement and bereavement care and were interpreted in terms of their universal essence (Moustakas 1994). Experiences are bound up in the context in which they are lived, for example, the physical, social and cultural environment of a care home. They naturally reflect engagement with the phenomenon rather than the phenomenon being a separate entity (Caelli 2000, Benner 1994). This indicates that the constructivist approach using the Duquesne University style of phenomenology in this study could provide a broad understanding of activity in bereavement care. Descriptions and interpretations of what bereavement care is, and at times what it is not or what is concealed, revealed care for the bereaved as a whole (Benner 1994, Moustakas 1994). A traditional methodology may have resulted in delineation of aspects of caring for bereaved older people, for example, the phenomenon

of care, or of bereavement. However, a complete practical understanding of the phenomenon of bereavement care may not have been achievable.

As previously identified, a key factor in this research was that it should lead to practice enhancement. This is increasingly being demanded by research funding bodies and the public in terms of value for money (Landry, Amara and Lamari 2001). New theoretical knowledge is continually required to inform and provide a basis for change. In health services research practical application is necessary to encourage development of new ways of providing services, or enhancement of existing services. For example, the transfer of research evidence to practice has been beneficial in the field of aphasiology through the introduction of new techniques for managing the condition (Kagan et al 2010). The outcomes of the current study provide a clear pathway for the enhancement of bereavement care for older people by increasing their chance of receiving support that is tailored to needs. Descriptions of experiences explored in interviews and analysed in detail provided the elements from which the key themes presented in Chapter 5 arose. In addition, sufficiently detailed descriptions and explanations fed into recommendations and criteria in the guidelines (Chapter 6). Had the details been less explicit the development of clear and relevant criteria may not have been feasible, or would have been less valid.

Obtaining a range of views

The exploratory study was concerned with interviewing healthcare staff and bereaved older people. Obtaining a comprehensive overall impression of bereavement care depended on identification, recruitment and interviewing a maximum variation sample (Chapple and Ziebland 2010). Recruitment and sampling for the study was challenging but through continued efforts a range of healthcare staff in the areas of interest gave their perspectives. However, one unrepresented group whose views may have added a useful insight to care of the bereaved were junior doctors in hospital settings whose roles may include communication with patient's relatives, palliative care, and death certification.

Sampling challenges also restricted the gathering of a range of perspectives from bereaved older people. Six took part in interviews for the study which was half the number that was originally anticipated. This was a limitation that meant those perspectives of bereaved relatives other than spouses; bereavement care in care homes; people other than white British; and bereavement experiences of men were not fully explored. The recruitment strategy may have been a barrier to those who were not next of kin of the deceased, for example, siblings, parents, grand parents and friends. For healthcare staff to identify members of the wider family network or friends may have been difficult when support around the time of the death is usually directed at the nearest relative. In addition, it is appreciated that perspectives on bereavement may differ greatly across cultures and religions and the inclusion of older people from ethnic minority groups may have indicated useful criteria for the guidelines (Koffman et al 2005; Rosenblatt 2008). Each participant in the study had a contribution to make towards the emerging explanation of bereavement care and while it is acknowledged that generalisations cannot be made, there is no indication that their perspectives were unrepresentative of the wider white UK population of older people.

Collecting appropriate data

Data collection methods used in the study allowed exploration and interpretation of processes of interaction between healthcare staff and bereaved older people (Creswell 2007). The interview schedules developed appeared to open up conversations about bereavement and bereavement care and cover the range of topics in a logical format. In addition, the semi structured nature of the interview was flexible enough to allow interviewees in collaboration with the interviewer, to explore and develop ideas (Silverman 1997). However, the interview was framed to take the conversation in a direction it may not necessarily have taken otherwise and some were challenged to respond. To obtain useful ideas for practice development required some prompting for fuller details on perspectives and knowledge (Benner 1994). The information provided to participants prior to interviewing, however, identified that the data would be collected for this purpose. Information may have arisen naturally using open questioning, however, clarity was obtained by directly asking for suggestions. Main (2000) used a

similar procedure to create a protocol for general practice in which interview topics guided interviewees to provide suggestions for improvement. In support of using semi-structured interviewing to obtain suggestions for future improvements in services Legard, Keegan and Ward (2007) identified it as a positive note on which to conclude an interview. It also identifies, for participants, that the research is seen to have a practical purpose and that they may have active involvement in creating service developments. It could be argued that new developments in healthcare practice may never be achieved unless questions are asked that directly elicit suggestions and ideas, or the specific aim is framed from the outset.

Taking part in an interview was challenging for both healthcare staff and bereaved older people. Particular aspects that people found difficult were story telling to create narrative accounts, considering how bereavement care could be enhanced, and the emotional nature of the subject. Benner (1994) sees accounts of experiences as reducing options for creating false generality or ideology. However, though they had been informed prior to the interview that they would be asked to recount experiences, some interviewees only wanted to give facts and opinions as they would interpret them. In addition, some were unable to separate a particular experience from more generalised descriptions of what is done for bereaved older people. Others, however, were able to give detailed accounts of particular interactions between themselves and bereaved relatives that were rich sources of material for interpretation. Older people also found it difficult to remember in great detail their contacts with healthcare staff at the time around their bereavement. This may be due to the overwhelming nature of bereavement, their cognitive state, or contact with healthcare staff occurring in the midst of many other interactions.

Emotional responses to interview questioning for both relatives and staff at times restricted following up with additional probes that may have elicited more detail. In retrospect a more collaborative approach including more than one meeting with participants, particularly relatives, may have led to more open discussion of experiences. A two or three stage strategy for interviewing, like that suggested by Wengraf (2001), may be more useful than first envisaged, though time and monetary costs for the research, and

emotional costs for interviewees are risks in staged interviewing. Bereavement researchers have also found that this kind of partnership approach may be emotionally draining for the researcher and require careful attention to keeping personal experiences separate from that of the interviewee (Rowling 2009). The bracketing out of personal experiences was challenging in this study due to knowledge of the area, and experiences of bereavement. It was tempting to provide anecdotes of experiences, and on two occasions personal experiences were used to stimulate discussion. However, the effect was in opposition to that desired and, following this, care was taken to maintain concentration on the interviewee. Throughout the interviewing and analysis phases of the study efforts were made to consciously bracket out personal beliefs and experiences, and this became increasingly easier allowing focus to remain with the words of the interviewee (Smith, Flowers and Larkin 2009).

Bereavement was also thought to be too sensitive a topic for focus group discussion, however, with careful consideration of participant recruitment, creating a collaborative environment, and appropriate management of emotional discussions this approach may have generated ideas for the guidelines (Briller et al 2007). In addition, small groups with two researchers present increase the ability to hear what is said, or even what is left out (Benner 1994). However, the goal of the interview was to allow every participant to tell their story and being in a group may have stifled some voices.

Development of the guidelines and consultation

Discussion of a number of aspects of the study so far would seem to imply that development of guidelines from qualitative research is viable. SIGN (2008) further indicate that qualitative research is being increasingly used to inform some aspects of medical care. Best practice guidelines are regularly developed from reviewing qualitative studies and provide graded recommendations (The Joanna Briggs Institute [JBI] 2009). In addition, it has been used to design detailed complex interventions that tailor components to individual needs in, for example, coronary heart disease prevention strategies (Corrigan et al 2006). Bereavement, though not intrinsically a medical

concern, is something that many healthcare practitioners must get involved with in the course of their work. The development of guidelines that are informed by the voices of healthcare staff and bereaved older people appears to be relevant and practicable.

The main method used in the study to provide validation of the contents of the guidelines was consultation with key stakeholders. Poor response rate of study participants invited to provide feedback could have led to the assumption that the guidelines were unsuitable for use in practice settings. However, the small numbers who attended a group discussion or provided individual feedback were enthusiastic about the potential for improved bereavement support for older people across healthcare settings. Consultation, when widened out to include other contacts and colleagues with interest in bereavement and bereavement care provided further validation of contents and consensus on the value for practice. Additional validation was received from a participating bereaved older relative who added useful commentary about particular aspects that may have been helpful around the time of the spouse's death. However, during the feedback meeting much time was taken with retelling the story of the spouse's illness and death. A greater response rate from bereaved older people may have provided more clarification of which aspects they saw as beneficial, and which needed more development. It may also have identified aspects that had not been addressed. The consultation process, though protracted, led to the collection of comprehensive feedback on the contents of the guidelines and informed the process of finalisation of a version for use in practice.

7.2 The themes from the interview study

The analysis of the methods provided above allows the themes identified in interview data to be interpreted and discussed whilst bearing in mind the strengths and limitations outlined. Chambers (2003) described *criteria of utility* for evaluating qualitative research. Such factors as the accessibility of findings; relevance to interests of stakeholders; and credibility are considerations. However, on the whole the strengths of the methods and steps taken to minimise limitations increase the authenticity and trustworthiness of the findings (Lincoln and Guba 1985).

Bereavement care depends on an existing relationship between healthcare staff and a patient's or resident's relative

When one or more member of staff in the hospital ward, care home or community team develops a therapeutic relationship with a dying patient's family, supportive care for at least part of the bereavement journey is likely. Building this relationship is seen in other fields, for example, eating disorders as a key component of caring that may be healing and restorative (Wright 2010). Additionally, the value, in oncology and palliative care of '*opening relational space*' with families has been identified (McLeod et al 2010). Supportive relationships developed pre bereavement between healthcare staff and patients' families encourage involvement in care and a greater understanding of the illness trajectory. In this study the importance of relationships that enable care to extend beyond the death of the patient was identified by participants. Bereaved older people, however, had little experience of receiving consistent information and support in the lead up to the death, or being followed up in bereavement. This supports the work of Duke (1998), that found the bereaved were more likely to turn to their families and friends when they needed support.

Community nursing staff particularly based their practice of following up older people in bereavement on their beliefs that there was benefit from discussion about the death, the deceased, and emotional and social challenges with someone who knew the deceased and was involved in their care. In addition, bereaved older people, some who had contact and some who had not post bereavement, agreed that follow up care would only be helpful if the member of staff was familiar. Kissane (2008) also noted value in this type of ongoing interaction between healthcare staff and the bereaved. The value of listening to the relative's story and providing a quiet space for reflection was identified. The literature also indicates that talking with someone who knew the deceased may assist the bereaved relative to develop a discourse of their life with and without the deceased (Costello and Kendrick 2000). However, in common with Costello (2002) the findings of this study demonstrated complex responses to loss that were multi-faceted and shaped by social and cultural situations. Staff and relatives described complex factors impacting on bereavement and bereavement care, and overall response to their needs from

healthcare staff was inconsistent. Many factors are seen as outside the scope of healthcare services and continued bereavement follow up beyond an initial contact is more likely to be driven by health and social care needs than a desire to extend the supportive relationship. This may give the impression that bereavement related difficulties are illegitimate reasons for continued support from healthcare staff. Ongoing psychological concerns then become labeled as something other than grief, for example, depression. In addition, relatives who may seek support find that they have to invent a legitimate reason for a visit to the GP and find a suitable moment in which to engage the GP in conversation about the bereavement.

The relationship between healthcare staff and a patient's relative may end quickly after the death depending on where the ill person dies. The current situation indicates that potential care needs, lack of family support and feelings of vulnerability being ill addressed are high (Prigerson and Jacobs 2001). Staff, particularly in hospital wards are effectively bringing the relationship to an end while they are simultaneously supporting the relative at the time of the death. This dichotomy appears to threaten the supportive relationship built in the lead up to the death both for the bereaved and for staff members. Across the sectors the ability to carry on the relationship is compromised by the demands of caring for others and lack of resources in terms of staffing and time. The study supports the ideas that brief encounters with the bereaved, real or perceived professional boundaries, and poor continuity across sectors leads to little meaningful activity as regards bereavement care (Cobb 2008).

Bereavement support routinely becomes the domain of community staff post bereavement (Harris and Kendrick 1998). However, the current research revealed that bereaved older people whose dead relative did not fall under the care of community staff are less likely to be followed up in bereavement. Additionally, inconsistent notification procedures between the hospital and general practice compromise the likelihood of follow up taking place. Relatives of those who die suddenly also fall outside the scope of services when they may arguably have more need for emotional and practical support (Ott et al 2007). It therefore appears reasonable to suggest that community staff

should follow up bereaved older people with whom they have had no previous involvement. GPs may be in a position to do this through their ongoing relationship as the family doctor. Bereaved relatives welcome a contact from their GP in the immediate days following a loss. There may, however, be an opportunity for community nursing staff to also offer support to previously unknown bereaved older people. Initially low level support activities that use minimal resources may be all that is necessary, for example, making a phone call. Co-ordination of follow up contacts will, however, be necessary to avoid more than one person phoning or visiting. The acceptability of contacts from members of the community team who are not known to the bereaved is unclear, however, if needs are great it may well be that contact is welcomed.

Preparation for the end of the relative's life may not equate to preparedness for bereavement

In this study facilitating preparation of relatives of dying patients was seen by healthcare staff in all practice settings as their main role in terms of bereavement care. Preparing an older person for the death of someone close is complex and could be described in terms of factors that are facilitators or barriers. In support of efforts to prepare older relatives, the literature indicates that relatives who have accepted the reality of the impending death may suffer less distress in bereavement (Metzger and Gray 2008), while poor preparation may be related to complicated grieving trajectories (Barry, Kasl and Prigerson 2002). In the current study preparation was based on staff having effective interpersonal skills and experience of working with relatives that gave confidence to engage with families and provide the right level of information. When information is adequate and timely the relative may be able to anticipate the loss and make use of an opportunity to begin to consider what life may be like after the loss (Parkes and Prigerson 2010). This study indicates that grieving the loss before the death, and particularly for families to do this together with the ill person, may smooth transition into bereavement. However, anticipatory grief is a complex phenomenon that also may invoke negative emotions like death anxiety, despair and anger that do not mitigate the loss (Chapman and Pepler 1998, Duke 1998). In addition, overwhelming an older person with information about their spouse's illness may be unhelpful when their care and comfort are the greatest concern.

Older spouses in this study varied in how they prepared, and the level and type of information they required. Staff interviewees in the study indicated that older relatives may be resistant to a barrage of detail about their spouses' condition and wished care staff to concentrate on their comfort. Research by Payne et al (2010) on end of life issues in stroke care has indicated that some patients can feel overloaded with information when they do not wish to know very much. In addition, relatives avoided using the internet through fear of finding too much that may be distressing in nature (Payne et al 2010). However, in the current study two spouses who had high needs for information were frustrated when staff appeared to withhold, were unwilling or lacked the knowledge to provide details. Good communication in the patient, relative and healthcare staff triad was found by Hebert et al (2009) to be the best way to manage uncertainty and prepare for the death. The same research team also indicated that preparedness was based on knowledge, emotional needs, and practical planning for the death (Hebert et al 2009). In the current study staff identified the same goals, however, this appears to equate to preparing for the death, but may not be preparation for bereavement. Preparing the older person for loss of the spouse and how it may affect them did not come across as a strong theme in interviews. Reviewing literature on discussions between patients and physicians in palliative and end of life care Fine et al (2010) found that physicians tend to focus on technical aspects of care and avoid discussion of emotional concerns. The protracted time such discussions may take was found to be implicated in their reluctance. It may be that discussions between healthcare staff and relatives in this study about impending losses were also framed in this way and avoided by healthcare staff. Fine et al (2010) also identified that frequent interactions with physicians, staff ensuring the comfort of the patient, and being given the opportunity to discuss thoughts and feelings increased family satisfaction with end of life care. The themes developed in the literature review for the current study of physical effects, psychological effects (including loneliness), changed relationships and continuing bonds may provide direction for conversations that facilitate relatives' preparation for bereavement.

Assisting relatives to be prepared may be challenged when they wish to deny the reality of the situation, or hold on to hope for the ill person to recover.

This may not be entirely negative when, according to Parkes and Prigerson (2010), minimisation of the gravity of a spouse's illness does not necessarily mean relatives are unprepared for the death. This work indicates that relatives may know that the death is imminent but at the same time are able to continue to think and act as if it were not. Staff in the current study dealt with this situation by continuing to interact with families and encouraging them to redirect their hope towards a peaceful death. Nursing staff commonly used other family members or other members of the healthcare team, for example, doctors and chaplains to facilitate appropriate conversations with relatives. However, when accurate information was required healthcare staff were clear that this should be the responsibility of the appropriately trained individual, for example, a GP or district nurse in the community setting. This is supported by the work of Schildmann et al (2005) who investigated the training and competency of pre registration house officers in discussions of bad news. Pre-registration house officers who had been trained for communicating bad news frequently did so, and perceived themselves as prepared for the task. However, organisational factors were frequent barriers to clear communication. Adequate staffing levels, time and privacy are key concerns when communicating with relatives in a way that enables effective engagement and understanding of what is said.

Staff in the current study expressed reluctance to enter into discussion with relatives about possible time scales for when the death may occur knowing that predictions may be grossly inaccurate. This may be compounded by failure to recognise physiological signs of deterioration which, as identified by Odell, Victor and Oliver (2009) can lead to mismanagement of ill patients. Payne et al (2010) identified uncertainty in family members about the prognosis of their relative in acute stroke as a key concern. It was found that though relatives were aware that it was difficult for physicians to be certain and they found the information difficult to hear, they needed clarity. In addition, relatives described obtaining information in an ad hoc fashion that depended on waiting until staff wanted to talk, or grabbing opportunities to ask (Payne et al 2010). In the current study, bereaved relatives' experiences in the lead up to the death of their relative were similarly of variable engagement with staff, and varied levels of preparation. Other factors

identified were making assumptions about what relatives do and do not know, not offering information unless relatives ask, focusing on medical aspects, and putting a positive spin on the situation. As well as lack of discussion with family members in the lead up to the death, a further difficulty identified in recent research may be relatives' perceptions of futile interventions, for example, with people with heart failure (Small et al 2009). The desire of healthcare staff to be doing something was contrasted with relatives' desire to be with the dying person. The factors above appear to lead to a confusing impression of the situation and the death coming as a shock. In addition, unsatisfactory engagement with healthcare staff in the lead up to the spouse's death led to bereavement experiences that were characterised by rumination and guilt. It would not be unjustified to believe that this may also compromise coping and adaptation in bereavement.

Staff and relatives in the study indicated that the best preparation may result from open dialogue between the ill person, relatives, and staff. This is supported by Payne et al (2010) as a key theme in end of life stroke care. However, where the optimum position is on the continuum of preparedness remains unclear and it could be concluded that there is no position of being fully prepared. Consider though, end of life care in a care home for a resident who has reached extreme old age and is perceived as having had a 'good' life. The death may be expected, the family has dealt with all financial preparations, including disposal of property, and it is anticipated that distress will be minimal as the dying resident's quality of life was perceived as poor. On the face of it preparation appears to be complete and the relatives may be placed at the well prepared end of the continuum (Figure 9, p 148). However, because there are vastly differing circumstances of death and situations of families it may be that for most preparation lies somewhere between poorly prepared and well prepared. It may be that the only relatives who could be accurately placed on the continuum are those suddenly bereaved and those in a situation like that outlined above. The reality, however, may be that most family members experience a myriad of factors that influence preparation indicating that placing relatives on the continuum would not be recommended as something for use in practice to determine preparedness. It would be impossible to predict through short interactions between family members and

healthcare staff how someone may internalise information and how they may respond when the death occurs.

The (Open) Door to bereavement care is only slightly ajar

The Open Door provides a unique illustration (Figure 10, p 150) of the efforts that healthcare staff may make to support bereaved older people when there is no formal system of support available but a continued consciousness that bereavement may be problematic for the relative. Data analysis, however, indicates that the current situation may be that the Door is only slightly ajar and not particularly effective at giving sight of need. Calling it the Open Door, though it feels like a good analogy, does not in fact reflect that it may be more shut than open. To drop the word 'Open' and continue to refer to it only as the 'Door' may be the way to proceed. Further contact with healthcare staff through the Door may address certain aspects of bereavement, for example, clarification of events that led to the death. However, the emotional needs of the bereaved may not be entered into in the kind of brief encounters characterised. All aspects of the Door are informal in nature and whether or not formalisation or widening bereavement support would benefit the bereaved is unclear.

The most frequently offered aspect of the Door identified in this study was inviting further contact. Kissane (2008) stated that the open invitation sustains continuity of care for the bereaved, while the current study however, posits that the Door is not currently wide enough to facilitate any ongoing support. This aspect of the Door may therefore be appropriate for formalisation in some way (Cobb 2008, Parris et al 2007). Parris et al (2007) studied bereavement follow up meetings with an emergency department consultant and found that one in seven significant relatives accepted the offer of a meeting. Relatives in the present study iterated that they would have liked clarification of events that led to the death, or indicated through their rumination on the loss that a meeting of this type may answer questions. A formal appointment for a meeting may mean that bereaved older people are more likely to take up the opportunity to reach back into services.

Further contact after bereavement may naturally take place between the bereaved relative and their GP. However, bereavement related difficulties may not be seen by general practice staff or relatives as a valid reason for visiting the surgery. The study has identified a need for the full range of staff, including healthcare and administrative staff, in general practices to be more aware of the effects of bereavement on older people. There is a paucity of research on interactions that non medical or nursing staff may have with bereaved older people, for example, reception staff. However, while accessing the GP may be challenging, it appears that when older people with bereavement difficulties present to the GP they will be taken seriously.

Other aspects of the Door may have limited value as regards follow up support. Variability in information availability and provision was apparent across the healthcare settings in the research. Staff who had no written information to give relied on verbal explanations to bereaved older people of procedures that should take place after a death. However, how much is remembered and understood is unclear. Those who described providing information gave standard packs and relied on the information containing sources of support for the bereaved that they could access should they have a need. This allows staff to believe that they have opened a Door to bereavement services taking the emphasis away from any responsibility they may have for ongoing support. However, current unpublished research has shown that staffs' knowledge of the contents of bereavement information packs may be limited and decisions are made by staff about whether or not to give out the material (Hutchison, Wimpenny and Scott 2010).

Communication of a bereaved older person's needs from a ward or care home to the GP, could potentially open the Door to bereavement care from community services. However, current practice of death notification is unreliable at bringing the bereaved to the attention of GPs or district nurses and is more indicative of handing on responsibility than a supportive activity. It appears that the explicit barrier of the walls of the hospital or care home prevents effective communication about bereaved older people (Figure 11, p 163). In addition, many assumptions are made at this time about what is done in other sectors for bereaved older people and what the bereaved may

need. Apparent beliefs are that comprehensive support before the death and at the time of the death means that a relative may have less needs post bereavement, and that people who are experiencing bereavement difficulties will seek help. This lets those in institutional care off the hook as far as communication and sharing of information about the bereaved is concerned. Developments in this study would suggest that the time before the death may be when some assessment could take place to define what risk factors are present and whether or not communication of the person's needs, or structured follow up may be necessary.

Currently there is reliance on the family to support the bereaved older person and this is undoubtedly the most natural place for support to take place (Parkes and Prigerson 2010). This study indicates that the ability of the family to support is, however, compromised by factors like living a long distance away, family members also being bereaved by the same death, and aspects of the older person's bereavement response that may be difficult to openly discuss. Parkes and Prigerson (2010) suggested that some families cope with bereavement better than others through cohesiveness and secure attachments formed in childhood. This would suggest that the family provides an environment where emotional aspects of loss could be dealt with and discussed. However, bereaved older people in the current study were likely to identify the support they received from their family, particularly children, in terms of practical tasks. This is represented as restoration oriented coping in the Dual Process Model (Stroebe and Schut 1999). Loss orientated coping, also identified in the Dual Process Model, is likely to be part of family support though it may at times seem intangible and not openly acknowledged by the bereaved. Reliance by healthcare staff on the family to support negates the need for healthcare services to provide much in terms of bereavement care and effectively is shutting the Door. Staff may have some idea of whether families have the ability to provide support, though the family is generally a step away from the patient or resident lying outside the realms of healthcare.

Bereavement care supports the progression of the Rolling Ball of life

The fourth theme of the Rolling Ball illustrates bereavement not only as a journey in grieving a loss, but as part of the larger journey through life. The

figures developed (Figures 12, p 169 and 13, p 172) attempt to bring together the bereaved older person, bereavement care, and factors that may either facilitate or hinder the smooth rolling of the ball. They also bring together the first three themes extracted from the interview data. The Rolling Ball is used to describe the phenomenon of caring for bereaved older people within the complex environments of healthcare settings. They reflect a complex event, bereavement and bereavement care, as lived and experienced by the key players (Wertz 1985), bereaved older people and healthcare staff.

Initially a timeline diagram was developed to illustrate bereavement and bereavement care (Figure 14, p 181), however, it appeared to be too defined in terms of stages of grief and particular inputs of healthcare staff at certain times. As far as the relative's bereavement experience is concerned this is already represented in the Dual Process Model (Stroebe and Schut 1999). Interview data in this study supported the concepts of loss and restoration orientated coping, as well as oscillation and taking time out of grieving. In the Rolling Ball, loss orientated and restoration orientated coping are implicit, however, they could be made explicit. Factors that are illustrated are related to the social and cultural settings of the workplace where interactions take place between healthcare staff and bereaved older people, and in the context of the wider family and social place (Berger and Luckman 1966; p36-37).

Berger and Luckman (1966; p40-41) also identified the temporal dimension to inter-subjective reality where life is ordered by time. The Rolling Ball locates bereavement and bereavement care within a time schedule from pre bereavement when the death is inevitable to a time days or weeks after the death. However, it is a moment in time within the greater scale of the person's lifetime. It indicates a perceived short window of opportunity for healthcare staff to interact with the bereaved regarding the loss, while it also reflects the reality for bereaved older people that their loss will last a lifetime. Prolonged grief disorder may be apparent when symptoms persist for six months or more from first noticed (Prigerson, van der Werker and Maciejewski 2008), though after the passing of the optimum time for interaction with healthcare staff. Bonanno et al (2002), and Bonanno, Nesse and Wortman (2004) also identified common bereavement trajectories, however, this level

of detail did not feature in interview data and was not included on the Rolling Ball.

Between the two Rolling Ball figures (hospital and care home staff, and community staff) the major difference appears to be in the positioning of the Door. Specifically, when community staff provide bereavement support it may appear later and continue for longer with the Door only coming into play when at least one bereavement follow up visit has taken place. The Rolling Ball was developed to illuminate older people's experiences of bereavement and indicate facilitators and barriers to effective bereavement care that may affect adjustment and coping. Staff may be able to identify within the figures factors that restrict the bereavement care they provide, or about the bereavement responses of relatives that restrict coping.

7.3 The guidelines for bereavement care for older people

It has previously been suggested that the use of constructivist phenomenological methodology to describe experiences could feasibly lead to the practical application of the results (Caelli 2000). In this study practical application came about in the development of guidelines for bereavement care for older people. The interview study made it clear that variability in practice and organisational barriers across sectors and within practice settings were restricting follow up and the provision of appropriate support. This compliments the findings of research previously conducted in the three areas of interest that also reported development of recommendations for practice protocols or guidelines on bereavement care (Main 2000; Walsh et al 2008; Davidson 2003). In other practice areas bereavement care strategies delivered in the context of multidisciplinary healthcare have been described as integral, for example, in paediatric end of life care (Jennings 2005, Association of Children's Palliative Care 2010). They ensure that support is available to those bereaved relatives who may struggle to cope with their grief and require opportunities to discuss emotional and practical challenges. These studies emphasised the feasibility of developing guidelines. Additionally, Walsh, Foreman and Curry (2007) evaluated a bereavement programme at a large general hospital and found that it was used appropriately by the bereaved. Particular aspects that people found supportive were outreach contact and

information provision. Those who had been bereaved unexpectedly also found the service accessible and supportive. An education protocol, support and communication were key aspects identified as drivers of success.

The current study developed the scope of guidelines as a tool to promote support of bereaved older people through their bereavement journey. It was designed for sharing across sectors and to reflect the fact that contacts between healthcare staff and older people around the time of bereavement straddle sectors. The transition for the relative from anticipating the loss to being bereaved may take place in tandem with a move from intense involvement of healthcare services to a near or complete withdrawal of contacts. This may be a time of vulnerability for the bereaved but also a time when they are at risk of '*falling through the net*' and becoming invisible to the system. Guidelines that facilitate transition of care between services therefore seem appropriate.

Recommendations and criteria in the guidelines were designed to address the key effects of bereavement on older people that were identified in the literature review (Chapter 2) and the interview analysis (Chapter 5). The literature review found physical effects, psychosocial effects (including loneliness), changed relationships, and continuing bonds with self and others to be important considerations. In developing opportunities for interactions between healthcare staff and the bereaved pre and post bereavement, some factors may be addressed. The physical and psychosocial effects of bereavement may be identified through contacts and meetings where assessment and surveillance can take place. Existing health conditions, age related frailty and social factors, for example, caring characteristics are key predictors of ongoing mental and physical health difficulties (Siegel and Kuykendall 1990, Burton, Haley and Small 2006, Stroebe, Schut and Stroebe 2007). These may be identified through a relationship with a bereaved older person and be a catalyst for communication of concerns. However, interview data did not identify bereavement as having an effect on health though the guidelines may be a tool for raising awareness. Interviewees, relatives and healthcare staff, were not specifically asked about bereavement and its effect

on health, and unless participants had particular knowledge in the area the connection may not be recognised.

Supportive measures in the guidelines may also acknowledge changed relationships and continuing bonds with the deceased. Contacts and bereavement visits mean that healthcare staff can listen and respond to relatives' questions and support development of narrative about the life and death of the deceased (Costello 1999a, Walter 1996). There may, however, be resistance to spending time listening and talking with bereaved older people in this way when practitioners have heavy workloads. This may be a role that families fulfill, or if not may be more relevant for the voluntary sector. However, unanswered questions about the time leading up to the death can only be addressed by healthcare staff who were present. Loneliness, though clearly acknowledged as a key concern for bereaved older people, may also be difficult to address from within healthcare settings. Again support may fall to social care services, or where available the voluntary sector. However, in the present context of local authority funding cuts the reality may be that services are restricted and there are increased unmet needs in older people (The King's Fund 2010).

Development of the guidelines was a planned phase of the study that initially seemed to be separate from the interview study, however, it occurred naturally and dove tailed with analysis of the interview data. This meant that the interview data supported the development of guidelines and indicated that the aims of the study were appropriate and achievable. The guidelines facilitate ongoing support from a time prior to the death to a time post bereavement. It could also be seen as widening the Door to bereavement care that was identified to be currently only slightly ajar. The resulting concern in budget conscious healthcare services is that there would be additional cost and time implications. However, the majority of interventions suggested are believed to be low cost in terms of staff time and resource costs. It could also be argued that the small cost at the time of the bereavement or in the very early days and weeks may negate additional expense at a later stage when a relative may need intervention for a complicated grief trajectory (Onrust et al 2008, Small et al 2009). Opening

the Door wider also raises the potential for an overwhelming desire to access services that exceeds the capacity to respond. However, previously hospice bereavement services have found that providing contact details and stressing that services are available has not resulted in high numbers of bereaved relatives making an approach (Stephen et al 2006). This would suggest that a more formal appointment system may not be something that all bereaved older people would consider beneficial, and that people will only attend if and when they have particular needs or difficulties. Follow up visits and meetings offered should, however, be delivered by a specified person who is available and is prepared to discuss events that led to the death and potentially bereavement related concerns. This would require services to be managed in a way that facilitates such meetings. Making arrangements of this nature may be challenging in some settings, particularly hospital wards and care homes. However, it could be argued that bereaved relatives have a right to have questions answered and their health and social care needs addressed. Providing some follow up support may additionally require training for practitioners in terms of bereavement and provision of appropriate bereavement support (Walsh, Foreman and Curry 2007). Again financial constraints may restrict uptake of continuing professional education opportunities by healthcare staff.

Consultation on the guidelines further indicated that it could potentially be used as an educational tool. This concurred with staff interviewees' views that there was a lack of training in bereavement care both at undergraduate level and in terms of continuing professional education. This is an additional use of the guidelines to that of service enhancement, the main aim for the project. However, NICE indicate that a key aim of guidelines is education and training of healthcare professionals (NICE 2009). In addition, Matzo et al (2003) indicate that interactive teaching on grief, loss and bereavement should be a key area in the undergraduate curriculum for nurses. The guidelines could potentially be developed in this way, and delivered as a topic for a one off practice development session, as part of a short course on grief and loss, or as a module in palliative and end of life care training. Paradoxically, use of the guidelines to facilitate education may enhance the potential for the guidelines to be used in practice. However, it should be more than a training tool in

order to enhance care and support for older people. Recommendations and criteria in the guidelines need ongoing work and commitment over time when a short term training initiative may lose momentum within a short period. In the long term, recommendations will have a better chance of becoming integrated in practice if they are used for both practice development and education.

The completion of the guidelines for bereavement care for older people is extremely pertinent within the framework of current policy work around end of life care and bereavement. Of particular relevance is *Shaping Bereavement Care*, the Scottish Government's policy development work on planning and implementation of bereavement services in NHS boards (The Scottish Government 2011). The guidelines developed in this study complement the wider recommendations of *Shaping Bereavement Care*, adding specific detail that will identify, for staff, the kind of steps that can be taken to facilitate the bereavement journey of older people. However, there may be a need for recommendations to be more generally applicable to all adults. The development of the guidelines in this way is believed to be feasible because much of the interview data, particularly collected from healthcare staff, was non specific as regards age, or gender. Some additional exploration may be necessary with younger bereaved relatives, or including literature and research on bereavement experiences of all adults. Maintaining the focus on older people, however, raises awareness of how they may be affected by bereavement. Considering that a sharp rise in the population of older people in Scotland is predicted over the next two decades (The Scottish Executive 2007; p15), it would appear that it is entirely legitimate for the guidelines to remain specific to this group.

Use of the guidelines in practice will be necessary to evaluate the affect on bereavement outcomes of older people and assist healthcare staff to provide appropriate support. However, Schut and Stroebe (2005) identified that efficacy of routine intervention with the bereaved receives no quantified support. The recommendations in the guidelines should be regarded as supportive measures rather than interventions as there is no intention of providing specialised counselling or treatment. Parkes and Prigerson (2010)

identified the support that medical and nursing staff can give to relatives through the psychological transitions that they face in bereavement. Providing information and *psychological first aid*, implicitly included in the guidelines, are referred to as legitimate roles of health professionals.

7.4 Implications for practice

The guidelines for bereavement care were designed for use in the healthcare settings of interest in the study by a range of staff who may have contact with bereaved older people in the course of their work. That the research was relevant for practice and had clear outputs that may be used to enhance current care was a key driver for the project. There are consequently implications for practice in terms of dissemination of the guidelines and implementation in healthcare settings. Some major factors to consider are discussed in this section.

Implementation of the guidelines

Consultation on the draft guidelines found that they were acceptable and suitable for practice. However, SIGN (2008) identifies a gap between development of guidelines and implementation in practice. Barriers to overcome in healthcare settings may be in relation to financial constraints; skill mix; local standards not being in line with desired standards; knowledge, attitudes and skills of practitioners (SIGN 2008). Following completion of the current project some work will be carried out to introduce the guidelines to the practice areas of interest, initially via members of the advisory group for the project. They may act as entry points to meeting local practitioners who may be able to use the guidelines in their clinical areas. Implementation in the care home sector may be pursued through the Scottish Commission for the Regulation of Care. The six stage process developed by Landry, Amara and Lamari (2001) may usefully inform a dissemination strategy. The authors identified that the crucial stage of the process is transmission, or informing practitioners of the results of the study. Initially healthcare staff may be encouraged to read and engage with the guidelines, then make efforts to use them in practice and apply them to decision making. However, Landry, Amara and Lamari (2001) further indicate that moving higher up the ladder of successful knowledge utilisation depends on whether the research reflects the

users' priorities, and the influence of external research funding bodies. However, Grimshaw et al (2004) identified the lack of an evidence base for successful dissemination and implementation strategies for clinical guidelines. Consideration of the likely benefits and costs of introduction in practice is necessary, particularly in terms of changes in practitioners' behavior.

As identified above completion of the study and specifically the guidelines for bereavement care for older people is extremely pertinent within the framework of national policy work around end of life care and bereavement. It complements and could be used to support statements in *Living and Dying Well* (The Scottish Government 2008a), which recommends the introduction of palliative care standards including bereavement care equitably across all care settings. However, it has particular relevance to *Shaping Bereavement Care*, the Scottish Government's new policy on planning and implementation of bereavement services in NHS boards (The Scottish Government 2011). This policy may be an important vehicle that could carry the implementation of the guidelines for bereavement care for older people forward in healthcare practice.

Staff training is a further important consideration for implementation of the guidelines in practice. The work carried out during this project has indicated that although bereavement care is already a key component of general healthcare there is uncertainty around what may be best to do for the bereaved. Lack of confidence in interactions with the bereaved and perceptions of poor knowledge about bereavement appear to hold staff back from meaningful interaction. The introduction of the guidelines to practice may partially address such concerns. However, it is anticipated that introduction of the guidelines will incur costs for healthcare staff and institutions in terms of the opportunity costs of staff time and monetary costs for provision of training. In addition, for staff, increasing engagement with bereaved older people may have a short or long term emotional cost.

Potential of the guidelines to enhance practice

The themes developed in the interview study indicate that bereavement support based on the pre death relationship between a patient's family and

healthcare staff enables sustained support in bereavement. This is also supported by Kissane (2008) who adds that healthcare staffs' contribution to a support programme is vital. The guidelines provide a systematic approach to support for the bereaved that may be provided by a range of disciplines. However, targeted support and specific interventions for complicated grief (Kissane 2008) are not goals for the guidelines.

The guidelines for bereavement care for older people contain many criteria that indicate what is already done in practice settings for the bereaved. They are, however, brought together in the document in written format to provide a framework of support for an older person's bereavement journey. Additional criteria in the guidelines may be viewed as indicating areas for practice development (see Chapter 6). These include recommendations about assessment, facilitating ongoing support, and follow up from non community staff. Achievement in practice may initially be challenging for healthcare staff, however, criteria presented break the recommendations into small steps. Within the recommendation there may be criteria that are already being carried out, and gradually adding in others and embedding them in practice may be possible. In the example of follow up from non community staff (Figure 21, p190) taking low level steps like sending a sympathy card may be feasible initially, and at a later time staff may enhance that level of support by carrying out a follow up phone call. This kind of approach would satisfy a key outcome for the guidelines that staff should use it to consider how they currently interact with bereaved older people and how they may develop their practice.

Opening up communication channels across sectors about bereaved older people was also a key outcome of use of the guidelines in practice. It is believed that reading the guidelines will assist staff to understand each other's roles and to be able to identify who it may be feasible to build links with and when. For example, when a hospital nurse has concerns about a bereaved older person, discussion with the GP may result in a follow up plan (Kissane 2008). The guidelines introduce an assessment tool that may be used to identify risk factors for complicated grieving trajectories, and in conjunction with knowledge of the person (Relf 2008), may lead to appropriate sharing of

information. This, however, would only be done in collaboration with the relative and with their permission. Risk factor assessment in the guidelines is kept simple and could be carried out informally through conversation with the relative. It is worth noting here that a minority of people will have increased risk of prolonged physical and mental health problems and assessment can identify concerns and indicate appropriate care decisions (Relf 2008). Risk factor assessment will enable focusing of help where it is most needed (Schut et al 2001).

For older people – increased likelihood of being offered support regarding their bereavement journey

The section above has already indicated that the guidelines provide a framework for offering support to older people throughout their bereavement journey. When healthcare staff use the guidelines to inform their practice it could be envisaged that older people will be more consistently offered support. Relf (2008) indicated that proactively offering support may mitigate the health risks of bereavement. However, it should be acknowledged that most older people will adapt in their own time with the support of their social network (Metzger and Gray 2008).

In general, recommendations in the guidelines identify small things that may be considered to be low level support interventions that healthcare staff can do and that bereaved older people will appreciate and find comforting (Kissane 2008). Importantly for the bereaved, recommendations included in the guidelines provide opportunities for them to clarify events that led to the death, ask questions and talk about how they have been affected by the loss. When staff are responsive to the issues raised, according to Kissane (2008), this kind of discussion will bring about active grieving.

Raise awareness of bereavement and older people

Consultation on the guidelines also indicated that they may bring bereavement responses and needs of older people to the attention of healthcare staff. A short life working group as part of work around *Living and Dying Well* has identified lack of public and professional engagement in discussion about grief and loss as a factor that leads to the bereaved being socially isolated (NHS

Scotland 2010). The work group considered that health care professionals should be able to engage in appropriate discussions with families and colleagues. The introduction of the guidelines to practice areas may assist staff to improve their understanding of bereavement in older people and may mean that they are more responsive or proactive in discussing issues with older people throughout their bereavement journey. In addition, staff who have improved understanding may be more likely to enhance and expand the range of support activities they are willing to provide.

Educational resource

This final and potentially most important implication for the guidelines in practice is that, as previously identified, it may be a useful resource for the training of healthcare staff. Staff participants in the study frequently said that they had received little or no training on bereavement care, and those engaged in providing staff training were interested in its development as a training tool. In common with this study, *Shaping Bereavement Care* (The Scottish Government 2011) also identifies lack of training and support in bereavement care and provides a framework for training designed to support the NHS work force to enhance bereavement care. In this study the aims of the guidelines will not be achieved without providing opportunities for education and training for staff in bereavement care.

The Scottish Government (2011) recommends that training focuses on practical, psychological and socio-cultural aspects of care. The guidelines developed, however, address the two former aspects but may only partially address the latter. The participant population in the research was white British and it could be considered a limitation that the study did not examine bereavement and older adults from minority ethnic groups. In addition, spiritual concerns in bereavement are not well addressed as they did not feature heavily in the data collected. However, socio-cultural aspects are recognised in terms of the context in which the older person lives, and the role of the wider family and community in providing support. Some additional work may need to be carried out in relation to preparing an educational intervention that covers all aspects of bereavement and bereavement care.

Previous research has also identified tiered levels of training (Stephen et al 2009) in which the guidelines may be useful at foundation and in role specific courses. Particular areas where education on grief and bereavement may take place are in undergraduate education, continuous professional development courses for post graduates, and in inter-professional education. It may also be part of induction training for particular roles or working environments. Use of the guidelines to facilitate staff training and also as a practical tool to inform support provided in healthcare settings may reinforce the relevance of consistently providing high quality care to bereaved older people. The guidelines may then be regarded as a valued decision making tool for the healthcare practitioner.

7.5 The direction of future research

The development of the guidelines for bereavement care for older people clearly indicates that future research should take the form of testing the tool in practice. It may be anticipated that auditing the guidelines will highlight areas where improvement has taken place and areas where further improvement may be helpful. Audit criteria that are relevant for the different practice areas may be built into the guidelines and outlined explicitly in an implementation package (Bowker et al 2008). However, audit of the bereavement care guidelines may be difficult to carry out if it is not seen as a clinical priority area. In addition, pinpointing criteria that are auditable or measurable may not be possible. What is measurable, for example, about 'expressing words of sympathy?' Some criteria may be more amenable to measurement, for example, follow up contacts with bereaved older people or communicating with other services about the bereaved. In terms of measuring what desirable outcomes may be for healthcare staff, bereaved older people, or for healthcare services this may also be restricted. What helped a bereaved older person to adapt and cope could be difficult to attribute to a supportive activity carried out by hospital staff at the time of the death. Ritchie (2007) recommends the use of qualitative methods for evaluation of a service or interventions. Aspects for consideration are structural factors contributing to the service, how the service is delivered, and effectiveness of the service. Alternatively, a longitudinal study design to assess changes in the frequency of interactions, content of interactions, and type of support activities carried out following

introduction of the guidelines may be possible. Assessment may indicate that using the guidelines means people are supported more consistently, but it may not be the factor that determines adaptation to loss as people will progress through bereavement and over time most will adapt (Stroebe, Schut and Stroebe 2007).

Healthcare staff may find that using the guidelines enables them to be better informed about bereavement and bereavement care, and to interact with bereaved older people in a more proactive way. There may also be benefits for the service if it is seen that staff respond more flexibly to the diversity of bereavement situations and that a more equitable response is provided. Testing the guidelines may feasibly identify enhancements to healthcare staffs' practice and to healthcare services responses to bereavement that was a major aim of the study. Quantitative measurement may identify the number of times a staff member consulted the guidelines, the criteria used each time a staff member has contact with a bereaved older relative, the frequency of using criteria in a set period, new criteria introduced to practice and frequency of use. In addition, the proposed outcomes from using the guidelines indicated in Chapter 6 may be useful criteria for an assessment, however, they may not currently be quantitatively measurable. Examples are, consistent care for bereaved older people whatever the circumstances or setting; support needs are identified and addressed; and communication of support needs. Outcomes proposed for healthcare staff from using the guidelines were, for example, responding flexibly to the diverse range of needs of bereaved individuals; and being more confident to interact with bereaved older people.

Factors like organisational aspects of using the guidelines, the effects on bereaved older people, and the different contexts of delivery of bereavement care may be amenable to being examined using qualitative research to determine usefulness in practice (Ritchie 2007). This would be helpful to identify staffs' thoughts and opinions about using the guidelines in practice, and to reflect on how their practice and knowledge changes. Staff may be able to consider how it enhances and benefits the service they provide, what barriers there may be to using the guidelines, and its limitations. Previous

evaluation studies have successfully used qualitative methods to identify the effects of introducing new ways of working in health and social care services. Hodge et al (2010) evaluated one-day-a-week therapeutic communities for people with personality disorder and found that staffs' improved knowledge changed thinking as regards care. In addition, a care home support team developed to reduce abuse in long-term care was evaluated qualitatively and found improvements in communication between staff, improved knowledge and confidence, and quality of care (Lawrence and Banerjee 2010).

The development of an intervention study to evaluate the guidelines could provide the most useful information to assess the use of the guidelines in practice. This would involve comparison of outcomes in an intervention group with a control group. An example of a potential study proposal may be:

- Development of measurable outcome criteria;
- Recruitment of research sites in general practice and community nursing; hospital wards; and care homes;
- Random allocation to intervention groups or usual care:
 - Group 1. Introducing the guidelines to practice in a number of research sites along with a training programme
 - Group 2. Introducing the guidelines alone
 - Group 3. Usual care
- Statistical analysis of differences in outcome measures.

There may also be the potential for the guidelines for bereavement care for older people to be developed and measured as part of a long term complex intervention strategy for improving health outcomes of older people. Problem definition, intervention and evaluation are the key components for a complex intervention study, developed simultaneously to determine effectiveness in terms of outcomes for older people and cost effectiveness for healthcare services (Campbell et al 2007). All three aspects, in terms of bereavement care for older people, have been explored and developed in this study and subsequent writing of the thesis. The challenge is now to see the guidelines, either alone or as part of a wider strategy, applied in practice and impact determined.

CHAPTER 8.

CONCLUSIONS

The research presented in this thesis analysed bereavement care as it is currently provided to older people, explored suitable enhancements to care and provided guidelines for healthcare staff to use to inform interactions with the bereaved older person. This final concluding chapter will identify the contribution of the research within the context of current demands on UK healthcare services. It will also indicate those for whom the research has practical application and interest, comment on the ability of the chosen methods to achieve the aims of the study, identify the potential for the themes from data analysis to be developed in practice, and recognise the potential impact of using the guidelines in healthcare settings.

8.1 Relevance of the research for healthcare practice and older people

The exploration and development of bereavement care for older people that took place through this study was set within the context of a rising population of older people in the UK (Office for National Statistics 2010). In conjunction with increasing pressure on healthcare services to reduce costs this indicates necessity to develop strategies that enable older people to cope and be independent. Loss through death is a factor that inhibits physical, emotional and social well being in older people. The study has identified through the guidelines, a range of recommendations and criteria for healthcare staff to use to inform and enhance care currently provided to bereaved older people. The potential for the guidelines to promote consistent interactions with bereaved older people, respond to needs and support coping was identified in the consultation process.

Development of the guidelines at this time complements current policy development work on bereavement in healthcare settings (The Scottish Government 2011). The policy, Shaping Bereavement Care, provides recommendations for health boards in Scotland for development of high quality bereavement care services. Parallel development of recommendations for bereavement care in particular specialties and healthcare settings is encouraged through Shaping Bereavement Care. In some areas services are

well developed, for example, palliative care and children's services. For other groups, including older people, bereavement care is less well developed, and there are particular gaps in general healthcare services. The research carried out in this project and the guidelines developed contribute to the agenda of Shaping Bereavement Care by providing healthcare staff with opportunities for appropriate development of practice in caring for bereaved older people.

The thesis and the guidelines are relevant to healthcare staff in the three settings in which study participants were located, namely general practice and community nursing, hospital wards and care homes. These are non specialised areas where healthcare staff have contact with older people who have recently experienced the loss of a spouse, partner, close family member or friend. The research and the guidelines may be of interest and have practical application for all levels of medical, nursing and care staff. Staff may be able to identify criteria contained in the guidelines that could be adopted in their current practice to enable provision of holistic support to bereaved older people.

The research has identified that the input of healthcare staff is crucial to the delivery of bereavement care and achievement of support goals that may influence how older people cope with loss. Their interest in the research outputs and recognition of relevance to their practice is clearly vital to introduction and implementation in practice. Criteria in the guidelines may also inform interactions with bereaved older people and promote a more consistent and equitable approach to follow up. In addition, use of the guidelines is a practical way in which staff can demonstrate activities that enhance bereavement care practice. For the care home sector, the adoption of the guidelines may assist staff to achieve a range of objectives of The Care Commission (2009). Administrative and reception staff in healthcare settings may also find value from engaging with certain sections of the guidelines that are relevant to the timing of their involvement with relatives. In addition, reading the guidelines may raise awareness of the ways in which bereavement affects older people and encourage meaningful interactions as well as general discussion of end of life issues.

Use of the AGREE tool (SIGN 2008) to validate the process of developing the guidelines and criteria included in recommendations demonstrated the feasibility of using qualitative research to develop guidelines that is relevant and practicable. Qualitative exploration is recommended as a key component of future work in the development of guidelines, protocols and policies to form part of the hierarchy of evidence for an intervention strategy. In a similar way, it is currently used in the development of complex intervention studies in healthcare that use a range of methods (Medical Research Council 2000).

8.2 Application of the defined methodology and methods

The data generated in the interview study were detailed and relevant for current practice and for potential enhancement of bereavement care. The feasibility and relevance of development of guidelines for practice that could be shared across settings was established. The process of development was found to progress naturally from data analysis. However, usefulness in practice of such guidelines may be compromised by resource constraints on services particularly in the NHS.

As indicated above interview data fed naturally into the process of developing the guidelines and it was possible to establish a workable layout for recommendations and criteria. In addition, discussions with interviewees regarding gaps in bereavement care provision and suggestions for items that could be included clearly established important factors to consider. Previous research literature, policy documents and existing guidelines provided valuable sources for validation of criteria from interview data and ideas for the layout of the guidelines. Research work in accident and emergency and intensive care settings was particularly useful. However, research in some areas was limited and there was little to support some criteria in the guidelines, for example, in the care home sector or on communication between settings about the bereaved.

Focus group discussion with healthcare staff from a range of settings provided validation of the guidelines and support for implementation in practice. However, poor re-engagement of staff participants in the second phase of the study could have compromised the process of validation. Widening the

consultation to other groups and key stakeholders with an interest in bereavement and bereavement care provided further indication that the guidelines would be a valued source of information for healthcare staff. However, this group may be more biased in their opinions about bereavement care and about the guidelines than the original sample. Their interest in the topic may have meant that they were more likely to respond positively to the guidelines.

8.3 Value of the themes to inform enhancement of bereavement care practice

The themes developed in the study that describe bereavement care were key to informing the development of appropriate guidelines for practice. The experiences of study participants greatly influenced development of the guidelines in terms of bereavement care and represent a progression, described by participants, from pre bereavement care, through care at the time of the death, to follow up in the weeks and months afterwards. Insight was gained into potential difficulties that older people may face in their bereavement journeys and what is currently done by healthcare staff to support bereaved older people.

The relationship between healthcare staff and a bereaved older person was identified as an important factor in determining what is done in terms of support. In the guidelines enhancements to care have been developed that support building therapeutic relationships with families in the lead up to a patient's death that may be continued after the death. In many cases, the relationship develops pre bereavement and preparing the patient and family for the death is a key activity. Factors that assist adequate preparation of older people for the death and for bereavement are built into the guidelines. Combined with knowledge of the person healthcare staff will be better equipped to help the relative acknowledge the likely events and be as prepared as they need to be for the loss.

Through the development of the themes from interview data healthcare staff may also be able to identify what they can do in their area of practice to open up the Door to bereavement care and increase their accessibility to the

bereaved. Communication between services about the bereaved is developed in the guidelines to promote consistent follow up of bereaved older people that widens the Door to support. Defined follow up contacts that encourage clarification of events that led to the death or allow the bereaved to develop narrative of the loss may increase the power of the Door to be responsive to needs. In addition, the provision of appropriate and accurate information that gives older people the opportunity to access support is developed in the guidelines and may also promote opening the Door a little wider. Where there is no established relationship between healthcare staff and a bereaved older person, for example, when the death has been sudden, opportunities have also been developed in the guidelines for follow up support and identification of needs.

The Rolling Ball theme originated in the words of study participants who indicated the content and timing of their own particular interactions with bereaved older people. In the guidelines, suggestions for enhancements are low cost in terms of time and money but may allow the bereaved older person to cope and adapt to their situation in a way that is appropriate for them.

Overall, the themes contain many examples of current practice that healthcare staff will personally or organisationally recognise and may consider as areas for development. The guidelines provide the tool with which enhancements could be taken forward to become embedded in practice with benefits for practitioners in terms of evidence based service development as well as for bereaved older people.

8.4 Impact of the guidelines in practice

The guidelines for bereavement care for older people have the potential to have an impact on healthcare staffs' practice, healthcare services, and on older people who experience loss. It is anticipated that healthcare staffs' individual practice may benefit from increased knowledge and understanding of the effects of bereavement on older people. This may drive those who have contact with bereaved relatives in the course of their work, as well as those with particular interest in end of life care, to consider how practice may develop. Constant pressures on health services to reduce costs and ensure

older people remain independent in the community are key to identification of steps a practitioner can reasonably take to support the bereaved. For example, improved knowledge of bereavement and the range of responses of older people may assist staff to recognise support activities that they can deliver.

Enhancement of bereavement care for older people in healthcare services may, at a general level, allow development of a more person centred approach to care. For caring to continue post bereavement demands engagement with older people on a higher level than that currently practiced and depicted in the themes developed in the research. To equitably offer support to all bereaved older people that takes account of personal preferences and needs would be a clear enhancement to current care. Costs in terms of staff time and priorities were identified in the research as barriers to healthcare services taking part in bereavement follow up. However, the study has identified that even low level acknowledgement and offers of support may negate the need for input at a later stage when specialist care may be necessary. Constraints on services will, however, continue to be a major concern in healthcare and reductions in staffing levels may ultimately reduce any impact of introducing the guidelines in practice.

The impact of introduction of the guidelines for bereavement care for older people may be difficult to identify or measure. However, its use in practice has the long term goal of improving interactions with healthcare staff. Interactions that are more effective at addressing concerns and difficulties that arise because of bereavement may be a key beneficial outcome. When healthcare staff understand how bereavement may impact on older people's emotional, physical and social health they will be better equipped to offer support that may make a difference. Communication about bereaved older people across sectors, and bringing in support from social care services or the voluntary sector may be ways in which difficulties can be addressed before they become unmanageable for the older person and their family.

In conclusion, the research and the guidelines provide an evidence base for enhancement of bereavement care in the practice areas studied.

Acknowledging the impact of bereavement and addressing older peoples' concerns about bereavement are clearly key factors for the engagement of healthcare staff to improve the physical, emotional and social wellbeing of older people. The use of the guidelines provides opportunities for healthcare staff to deliver appropriately supportive care through confident interaction with bereaved older people.

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APPENDIX 1

Methods for literature review

Search for relevant primary research studies

Searches specifically identified research published from 1990 up to the year in which the review was carried out (2009).

Types of research studies included were:

- qualitative studies – narrative, phenomenology, grounded theory, ethnography, case study;
- intervention studies – randomised controlled trials (treatment studies - counselling; practice based interventions), quasi-randomised studies, other intervention studies;
- quantitative studies other than interventions studies – longitudinal studies, regression analyses, case-control studies;
- descriptions or evaluations of services for bereaved older people.

Studies were relevant to, or included as participants:

- older people (≥ 65 years of age);
- short or long term bereaved;
- bereaved of spouse, sibling, parent, child, other relative, or friend;
- general practice and community nursing;
- general hospital wards;
- care homes.

Exclusion criteria:

- no specific age range, too wide an age range, or mean age of participants ≤ 60 years of age;
- studies set in non westernised cultures (other cultures may have different beliefs and customs around bereavement that would not be relevant to the setting in which the empirical research was carried out);
- pet bereavement;
- post bereavement sleep disorders;
- non-death aspects of loss;
- comparing men's and women's grief responses;

- studies set in non western countries;
- studies of bereaved relatives' impressions of end of life care.

Studies of experiences of bereavement

The electronic databases searched: MEDLINE, CINAHL, EMBASE, AgeInfo, and ASSIA. A different search strategy was developed for each database. Searching Medline and Cinahl was fairly straight forward, though the addition of multiple search terms (>3) reduced the number of hits dramatically. For example, it was intended to extend the search by using a number of terms to represent 'older people'. This appeared to over complicate the search and it was found that using the limit buttons on the user interface was the most effective way for the database to find a range of relevant references. Words to represent bereavement were also added, for example, grief and grieving. This also had the effect of reducing the number of hits. It became apparent that keeping the search simple was necessary to achieve a range of references. The search strategy used was:

1. Bereave*
2. limit to humans
3. limit to age 65 and over

This yielded 965 hits from Medline and 485 in Cinahl. When the terms for grief were added this was reduced to 450. The same search strategy used in Embase yielded 323 records. The AgeInfo database yielded 419 items and ASSIA identified 20. Many references were duplicated across databases. The titles and abstracts of papers identified by the searches were read and for those of interest full text articles were obtained. Articles were retrieved from e-journals available through the university library, the NHS e-library (since re-launched as The Knowledge Network¹²), and the inter-library loan service. Existing stocks of papers held in the research office were also searched for relevant material. Relevant references were exported from databases to the online RefWorks¹³ bibliographic management tool which was used for storage and to create in text referencing and reference lists throughout the project.

¹² The Knowledge Network <http://www.knowledge.scot.nhs.uk/home.aspx>

¹³ Refworks <http://www.refworks.com/>

Studies of bereavement in healthcare settings

Searches were performed in the Medline, Cinahl, ASSIA and Embase databases. Search terms used were bereave*; service*; care. Seventy seven hits were found using Medline and Cinahl combined, 127 in Embase, and 149 in ASSIA. When terms for older people i.e. aged; elderly were added the number of hits dramatically reduced.

Extract data and assess quality of studies

Data extraction and quality assessment forms were designed to assist the review process. Examples can be seen below (Appendices 1A and 1B). A variety of sources were used to inform the development of forms that were flexible to the different methodologies used in the papers identified (Sandelowski and Barroso 2003, Spencer et al. 2003, The Joanna Briggs Institute 2008). The forms were used to extract relevant data, assess the quality of each included study, and identify themes that represented the meaning of bereavement for older people. A quality marker (good, fair or poor) was allocated to each included study. Studies assessed as 'good', in general, had high clarity regarding congruity of methodology and theory with the objectives, analysis, interpretation and conclusions flowing logically throughout the study. A study judged as 'fair' was less clear in some aspects and, in general, had no specific methodology stated or the interpretation and conclusion did not tie in with the objectives for the study. Studies rated as 'poor' gave little information about methodology and methods and as a result were unfocused and lacked an audit trail.

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APPENDIX 1A

Data extraction form (example)

File number	Paper 1-10
Authors	Hockey, J.; Penhale, B.; Sibley, D.
Year	2001
Title	Landscapes of loss: spaces of memory, times of bereavement
Reference	Ageing and Society 21: 739-757
Database/citation list/conference proceeding	AgeInfo
Aims, objectives/research problem/significance	The study aimed to describe the practical and emotional challenges of sustaining a meaningful life as the surviving spouse. The paper focuses on the survivors' use of public and private spaces. Previous research has considered housing needs, social care and emotional difficulties. The authors see the use of space by the bereaved as an un-researched area that has significance to the older person faced with challenges of living alone.
Type/area of literature reviewed	Literature reviewed included work on memories and their connection to spaces; feelings of social isolation and victimisation in the bereaved that forces them to alter their use of spaces.
Methodology	Qualitative interview study, grounded theory.
Setting	A large city in the north of England and a neighbouring market town.
Sample – size, composition, type	20 older widowed people: 17 interviewees ≥ 70 years of age, 3 interviewees in late 60s. All bereaved ≥ 8 months. 16 bereaved between 1-9 years, 2 bereaved ≥ 18 years. All lived alone; half in sheltered housing, half in marital home.
Methods	Access to participants through wardens of sheltered housing, bereavement friendship groups, drop ins or personal contacts. Interview questions listed. General issues – how relationship with public space had changed, how domestic space was used differently or similarly. Specific issues – taking over partner's previous role, release from restrictions, social networks, economic status. Two researchers interviewed, taped and transcribed in full. Descriptions of interviewees homes taken as field notes. Transcripts read by all members of research team and descriptive codes agreed.
Analysis	Codes agreed and data stored under codes to facilitate theory generation. Themes for discussion arose from this process.

Validity	All researchers in team read all transcripts and agreed on coding.
Results	<p>Changes in the embodied experience of space. Many accounts given of minor changes (though these were often part of a major shift in the experience of living alone); meals and holidays were times when more evident changes arose; loneliness seen as permanent.</p> <p>Gains and losses. a) The type, position and shape of the home itself – security and isolation described for widows living in their own homes in quiet suburbs while this was less of an issue for those in terraced houses or sheltered accommodation. However, individual identities compromised for those in sheltered housing. b) Social relationships – new rules re. visiting family arose, development of reciprocal relationships (something to be gained for either party). c) Health – often provided reasons for going out, become more evident when alone, interdependent relationships. d) The dying trajectory – relationship with space depended on the dead partners dying trajectory. Those who’s partners died after a spell of illness were more likely to have gone on to use space in a more rewarding manner. Freedom often described as a gain, while sense of coupledness had been lost prior to the death due to the illness. e) Relationship with the dead – continuing bonds.</p>
Author’s conclusion/significance of findings for research/practice	The loss of a partner can precipitate small changes in use of space, the qualitative impact of which cannot be overestimated. Bereavement can transform the quality of the experience of space and the meanings attributed to space, place and objects. Meanings shift over time. Material surroundings carry significances acquired across lifetime and the experience following the death is mediated by changes that took place towards the end of the partner’s life.

APPENDIX 1B

Quality assessment form (example)

File number	Paper 1-10	
Reference	Hockey, J.; Penhale, B.; Sibley, D., 2001. Landscapes of loss: spaces of memory, times of bereavement. <i>Ageing and Society</i> 21: 739-757	
Research question	Clear/unclear	Clear To explore use of public and private space by spousal bereaved older people. Development of theory.
Theoretical framework	Explicit/unclear/not presented	Explicit Framed around knowledge of housing needs, social care and emotional difficulties following loss of a partner.
Methodology	Appropriate/inappropriate - theory, objectives, methods, analysis, interpretation, conclusions	Grounded theory entirely justified as a new area is being investigated. Social isolation, living alone often referred to as a challenge of being bereaved of a spouse.
Sampling strategy	Clear/unclear	Clear
Fieldwork methods	Described/not described	Described
Researcher relationships – observed, setting	Clear/unclear	Partially clear The researchers have previously carried out bereavement research and research with older people re social isolation. Relationship with some participants unclear as they mention personal contacts but don't explain who these were.
Researcher – agenda, preconceptions	Clear/unclear	Unclear
Ethical issues	Clear/unclear/Not discussed	Not discussed
Audit trail	Clear/unclear	Clear
Data analysis	Explained/unexplained	Explained Codes agreed and data stored under codes to facilitate theory

		generation. Themes for discussion arose from this process.
Quantitative evidence	Described/not described/not used	Not used
Deviant cases	Described/not described	Not described
Contribution	Worthiness	Adds to knowledge and theory of older people's experience of being bereaved of their spouse. The study addresses a previous gap in the literature and gives valued insight into how older people may organise their public and private use of space and illustrates the meanings this may have.
Overall quality	Good/fair/poor	Good

APPENDIX 2

Invitation letter: healthcare staff



07 October 2008

Bereavement Care for Older People Using NHS Services

Dear ,

As someone who may care for recently bereaved people from time to time, I am writing to invite you to take part in a research study about bereavement care provided to older people. I am carrying out the research as part of my study for a research degree (PhD). The study aims to explore what is done for bereaved older people who use NHS services, and to develop a guideline or protocol for care staff to use when caring for bereaved relatives.

In this regard I would like to invite you to take part in an interview, and/or a group discussion. The interview will explore your experiences of caring for recently bereaved older people, and how ward staff communicate with other services about the bereaved. It will also examine your thoughts and opinions about gaps in the service, how the service could be developed and what could be done for bereaved older people. The interview would be undertaken at the hospital and it would last between 30-40 minutes.

The data collected from the interviews will be used to develop a guideline or protocol for bereavement care for older people that could be used by staff across the services (general practice, hospital wards, nursing homes). When a draft is completed I will hold group discussions with staff to find out whether you think the contents are suitable and would work in practice. The group discussion would include staff from your ward and may include others working in general practices and nursing homes.

The attached reply slip invites you to indicate whether you would be interested in taking part in an interview and/or a group discussion. All information that you provide will be kept confidential and will be reported anonymously. You would be free to withdraw from the study at any time without giving a reason.

I hope that you are able to participate, as I want to be sure that I understand key issues about bereavement care practice. I also want to be sure that the results of the research are relevant to the care given by you and your colleagues to bereaved relatives. I have attached a sheet with more information about the study. If you have any questions about the project, please contact me on 01224 263150 or e-mail a.i.stephen@rgu.ac.uk.

If you decide that you would like to take part, please either contact me by phone or email or complete the attached reply slip and return it to me in the

FREEPOST envelope provided by **31st October 2008**. I will then contact you to arrange a suitable date and time for your interview.

Yours sincerely,

Audrey Stephen
CSO Research Training Fellow

Bereavement Care For Older People Using NHS Services

Name:

Job title:

Work address:
.....
.....

Telephone number:

email address:

I will take part in:	an interview	Please tick	<input type="checkbox"/>
	a focus group		<input type="checkbox"/>
	I am not interested in taking part		<input type="checkbox"/>

APPENDIX 3

Information sheet: healthcare staff



Information Sheet for Ward Staff

07 October 2008

Bereavement Care for Older People Using NHS Services

You are being invited to take part in a research study. Before you decide whether or not to participate, it is important to understand why the research is being done and what involvement will mean for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Feel free to ask the researcher if there is anything that is not clear or if you would like more information (contact details at the end of this information sheet). Take time to decide whether or not you wish to take part.

Part 1 of this information sheet tells you the purpose of this study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The study has been designed to explore current service provision for bereaved older people who use NHS services and to develop a guideline for practice. This may help you and your colleagues to make decisions about the care of bereaved older people and about communicating with other services about their needs.

Why have I been invited?

Staff who come into contact with recently bereaved people, the majority of whom are likely to be older people (≥ 65 years of age), are being invited to participate in an interview and/or a group discussion about bereavement care. Staff in other wards, general practices and care homes in North East Scotland will also be taking part.

Do I have to take part?

No, it is up to you to decide. If you are interested, please let the researcher know by filling in the reply slip attached to the letter or contacting her by phone or email. The researcher will then describe the study and go through this information sheet, which you will be able to keep. You will then be asked to sign a consent form to show you have agreed to take part. If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen if I decide to take part?

You will take part in a one to one interview with the researcher. The interview will take place at a convenient time at your place of work. The interview will last between 30 - 40 minutes and would preferably be recorded, if you are happy for that to happen. You will be asked about your experience of caring for bereaved older people and communication of information about the bereaved to other services. You will also be asked whether you think there is a need for enhancing services for bereaved older people and what kind of things could be done.

At a later stage of the study you may be asked to participate in a group meeting to discuss the suitability of a protocol for bereavement care that the researcher will develop from the interview data. The meeting will involve others from your ward and may also involve staff from general practices and nursing homes who are also taking part in the research. It will last about 1 hour and will take place at a convenient location.

Travelling expenses incurred by taking part in an interview or group discussion will be reimbursed.

The research will take three years to complete (from September 2007).

What are the possible benefits and disadvantages of taking part?

It cannot be promised that the study will help you but the information collected may be used to develop the care of recently bereaved older people who have contact with health care providers. The use of a guideline may reduce the impact of bereavement on services and on the health and well being of bereaved people.

By taking part in the study there will be a risk that the sensitive nature of the topic for discussion will cause distress. However, this will be kept to a minimum during the interviews as you will only be asked to recall experiences of caring for the bereaved in the course of your work. If you are upset by talking about your experiences then the researcher will be happy to discuss any issues that arise. NHS Grampian counselling service is also available for you to contact. Their telephone number is 01224 553663.

The involvement of staff who regularly have contact with bereaved older people is essential to the development of a guideline that is suitable for use in practice.

Will my taking part in the study be kept confidential?

Yes, all information that is collected during the course of the research will be kept strictly confidential according to the Data Protection Act 1998. Names and contact details will be stored separately from other data collected. Data will be reported anonymously in all reports, papers or presentations arising from the research. Data will be stored for 5 years and will be destroyed when it is no longer needed for the project. Anonymous data may be shared with other researchers.

This completes Part 1. If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the researcher's supervisor, Dr Sylvia Wilcock at The Robert Gordon University. Her telephone number is 01224 262612 and her email address is s.wilcock@rgu.ac.uk .

What will happen to the results of the research study?

Completion of the study will result in a guideline for the management of bereaved older people who have contact with general practice, hospital and care home services. It will be used by staff in wards, practices and homes as an aid to making decisions about care and communicating the needs of bereaved relatives to staff in other areas.

A report of the study will be written, results will be published in peer review journals and reported at one or more conferences. Participants will be given the results of the study in the form of a summarised report. A leaflet explaining the project and results will be made available to the public at general practices. You will not be identified in any report or publication.

Who is organising and funding the research?

The research is being undertaken by Audrey Stephen, a research fellow and PhD student at The Faculty of Health and Social Care at The Robert Gordon University, Aberdeen. The research is funded by The Chief Scientist Office (part of the Scottish Government Health Directorates).

Who has reviewed the study?

This study has been reviewed and approved by The North of Scotland Research Ethics Committee and NHS Grampian Research & Development Office. The Caldicott Guardian for Grampian was consulted regarding data

protection issues.

What happens next?

Please get in touch if you have any questions about the research or about this invitation to participate. If you do decide that you would like to take part in the research, please contact the researcher by phone or email or complete and return the attached reply slip in the FREEPOST envelope.

Contact for further information:

If you have any questions or would like any more information about this study, please contact:

Audrey Stephen, CSO Research Training Fellow, The Robert Gordon University
Telephone: 01224 263150 or e-mail a.i.stephen@rgu.ac.uk

APPENDIX 4

Invitation letter: bereaved older person



Name and address

September 2008

Dear (Name),

As someone who has been bereaved of a family member in recent years, I am writing to invite you to take part in a research study about bereavement care provided to older people. I am carrying out the project as part of my study for a research degree (PhD). Your District Nurse, (name), has already discussed the study with you. I would like to thank you for expressing an interest in taking part. The study aims to explore current care provided for the bereaved and to develop a guideline for staff to use when caring for recently bereaved people.

In this regard I would like you to consider taking part in an interview with me. The interview will explore your experiences of care you received in the time leading up to your bereavement, at the time of the bereavement and in the weeks and months following. It will also examine your thoughts and opinions about gaps in the services for the bereaved, and what could additionally be done for bereaved older people. I will interview you either at your home or at The Robert Gordon University, whichever you prefer. The interview will be recorded (with your permission) and will last about 30 minutes.

Information collected from the interviews will be used to develop a guideline for bereavement care that could be used by staff in general practices, hospital wards and care homes. When a draft is completed I will hold group discussions with participants to find out whether the contents are appropriate and would be helpful to recently bereaved people. The group discussion would involve other bereaved people who are taking part in the research.

The attached reply slip invites you to indicate whether you would be interested in taking part in an interview and/or a group discussion. All information that you provide will be kept confidential and will be reported anonymously. You would be free to withdraw from the study at any time without giving a reason.

I hope that you are able to participate, as I want to be sure that I get a clear picture of what is done for bereaved people. I have attached a sheet with

more information about the study. If you have any questions about the study, please contact me on 01224 263150 or e-mail a.i.stephen@rgu.ac.uk.

If you decide that you would like to take part, please either contact me by phone or email or complete the attached reply slip and return it to me in the FREEPOST envelope provided by **date**. I will then contact you to arrange a suitable date and time for your interview.

Yours sincerely,

Audrey Stephen
CSO Research Training Fellow

Bereavement Care for Older People

Name:

Address:
.....

Telephone number:

email address:

		Please tick
I will take part in:	an interview	<input type="checkbox"/>
	a focus group	<input type="checkbox"/>
I am not interested in taking part		<input type="checkbox"/>

APPENDIX 5

Information sheet: bereaved older person



Information Sheet

September 2008

Bereavement Care for Older People Using NHS Services

You are being invited to take part in a research study. You have already heard about the project from your (District Nurse). Before you decide whether or not to participate, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully (Part 1 tells you the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study). Talk to others about the study if you wish. Feel free to ask the researcher if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

The study has been designed to explore bereavement care provided to older people in NHS services, and to develop a guideline for staff to follow when caring for the bereaved.

Why have I been invited?

Dr Lawton has identified you as someone who has been bereaved of a family member within the last 5 years. A sample of recently bereaved people aged 65 years or more is required to participate in an interview with the researcher. Participants should have been bereaved for between 6 months and 5 years. The involvement in the study of recently bereaved people is essential to understanding how bereavement care is carried out.

Do I have to take part?

No, it is up to you to decide. Your (GP) will be able to provide independent advice about participating in the study. If you are interested, please let the researcher know by filling in the reply slip attached to the letter or contacting her by phone or email (details below). She will then describe the study and go

through this information sheet, which you will be able to keep. You will then be asked to sign a consent form to show you have agreed to take part. If you do decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen if I decide to take part?

If you decide to participate, you will take part in an interview and/or a group discussion with others. Interviews will be carried out either at The Robert Gordon University or in your home, whichever you would prefer, and at a time convenient for you. Your transport costs will be refunded.

The interview will last about 30 minutes and will be recorded (with your permission). You will be asked about

- your experiences of the care you received in the time leading up to your bereavement, at the time of the bereavement and in the days, weeks and months since;
- your needs and whether they were met;
- whether you think there are gaps in the services for bereaved relatives and what could be done to enhance care.

The researcher who will carry out the interview is an experienced bereavement care researcher and is a trained nurse. She has been through training to prepare her for interviewing.

Interviews are also being carried out with members of staff at general practices, hospital wards and care homes. Information that is collected from all the interviews will be used to develop the guideline for staff to use when caring for bereaved older people. At a later stage of the project the guideline will be shared with study participants and discussed at group meetings. The groups will contain 6-8 participants, will last about 1 hour and the discussions will be recorded. The meetings will take place at The Robert Gordon University (or other location) at a time convenient for everyone. Your transport costs will be refunded.

The purpose of the meeting is to explore your thoughts and opinions about the bereavement care guideline. What you say about the guideline will help to decide whether it will address the needs of bereaved older people. Separate group discussions will be run with members of staff from participating general practices, hospital wards and care homes.

What are the possible benefits and disadvantages of taking part?

There may be some risk of interviewees and group members becoming upset or distressed due to the sensitive nature of the topic. The researcher will support you through the process and, if you think you need it, will advise you where to find additional support. If you need further support Cruse Bereavement Care Scotland is a registered charity which offers free bereavement care and support to people who have experienced the loss of

someone close. They can be contacted on 01224 626199 (Aberdeen Branch) or 01738 444 178 (National Office). It cannot be promised that the study will help you personally but the information collected will be used to guide the care of other recently bereaved older people who have contact with health care providers.

The involvement of recently bereaved people is essential to the development of a guideline that is suitable for use in practice.

Will my taking part in the study be kept confidential?

Yes, all information that is collected during the research will be kept strictly confidential according to the Data Protection Act 1998. Names and contact details will be stored separately from other data collected. Data will be reported anonymously in all reports, papers and presentations arising from the research. Data will be stored for 5 years and will be destroyed when it is no longer needed for the project. Anonymous data may be shared with other researchers.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the researcher's supervisor, Dr Sylvia Wilcock at The Robert Gordon University. Her telephone number is 01224 262612 and her email address is s.wilcock@rgu.ac.uk

What will happen to the results of the research study?

Completion of the study will result in a guideline for the management of bereaved older people who have contact with general practice, hospital and care home staff.

A report of the study will be written, results will be published in medical and nursing journals and reported at one or more conferences. Participants will be given the results of the study in a summary report. A leaflet explaining the project and results will also be made available to patients at general practices. You will not be identified in any report or publication.

Who is organising and funding the research?

The research is being undertaken by Audrey Stephen, a research fellow and PhD student at The Faculty of Health and Social Care at The Robert Gordon University, Aberdeen. The research is funded by The Chief Scientist Office (part of the Scottish Government Health Directorates).

Who has reviewed the study?

This study has been reviewed and approved by The North of Scotland Research Ethics Committee and NHS Grampian Research & Development Office. The Caldicott Guardian for Grampian was consulted regarding data protection issues.

What happens next?

Please get in touch with the researcher if you have any questions about the research or about this invitation to participate. If you do decide that you would like to take part, please complete and return the reply slip attached to the letter or contact the researcher by phone or email. You will then be contacted with more information about the next steps.

Contact for further information:

Audrey Stephen, CSO Research Training Fellow, The Robert Gordon University
Telephone: 01224 263150 or e-mail a.i.stephen@rgu.ac.uk

APPENDIX 6

Topic guide: healthcare staff interview

Bereavement care for older people

Aims and objectives

The central aims of this study are to explore current service provision for bereaved older people who use NHS services, and to develop a protocol or guidelines for practice that will enable effective case management and communication about bereaved older people across the sectors.

Main objectives to explore:

- a) current management of recently bereaved older people;
- b) the interface between primary care and secondary care/independent sector/voluntary sector services regarding bereaved relatives;
- c) practitioners' and bereaved older people's impressions of gaps in the service and the perceived need for enhancement, ideas for service development.

Introduction

Aim: to introduce the research and set the context for the proceeding discussion.

- Introduce myself and RGU
- Introduce the study: for my PhD, it is about bereavement care for older people
- Information sheet, consent form
- Talk through key points:
 - Purpose of the interview
 - Length of the interview
 - Voluntary nature of participation
 - No questionnaire, more like a conversation
 - Recording of the interview
- Confidentiality and how findings will be reported
- No right or wrong answers, just say what you think
- Any questions

1. Background and personal circumstances

Aim: to introduce the respondent and highlight any key background issues that might influence their attitude towards bereavement care for older people.

- Themselves
 - Qualifications
 - Time qualified

- Previous posts
- Present job
- Their typical day at work
- The ward/practice/care home
 - Speciality
 - Age range of patients/residents
 - Staffing arrangements

2. Current management of bereaved older people

Aim: to establish what experiences the respondent has had of caring for recently bereaved older people, what is done, when and why.

- Description of an example of when bereavement care went well
 - Circumstances of the death
 - Time of day
 - Long or short term illness
 - Patient known to staff
 - The relatives
 - Relationship
 - Age
 - There at time of the death, or not
 - Known to staff
 - Home circumstances
 - What was done?
 - Needs of the relatives
 - Immediate care for the relatives
 - Follow up care
 - Who provided the care and how it was organised
- Description of an example of when bereavement care did not go well
 - Circumstances of the death
 - Time of day
 - Long or short term illness
 - Patient known to staff
 - The relatives
 - Relationship
 - Age
 - Number of relatives
 - There at time of the death, or not
 - Known to staff
 - Home circumstances
 - What was done?
 - Needs of the relatives
 - Immediate care for the relatives
 - Follow up care
 - Who provided the care and how it was organised

3. Thoughts and opinions about bereavement and bereavement care

Aim: explore the respondent's attitudes to bereavement and bereavement care and level of engagement with bereaved relatives.

- Challenges of caring for bereaved older people
 - Needs of bereaved older people
 - Difficulties of providing bereavement care
 - Why it is challenging
- Providing support
 - Level of priority for respondent
 - Level of priority for organisation
 - Reasons why it is important/not important
- Perceived benefits of supporting bereaved relatives
 - For the relatives
 - For yourself as a service provider
 - For your service or other services

4. Communication between services about bereaved relatives

Aim: to establish the level of communication with other services that occurs in practice. To explore the different factors instigating or impeding such action.

- Experiences of passing on information about bereaved older people
 - within the respondent's service
 - with other NHS services
 - with other agencies i.e. voluntary sector
- When information is shared
 - Importance of sharing information
 - Circumstances
 - Mechanism for passing on information
 - Whether information sharing would help
 - Who's responsibility
- Factors that impede information sharing

5. Enhancement of services for bereaved older people

Aim: to explore suggestions for how bereavement care might change in the future. What improvements could be made that would assist the grief journey of older people?

- Respondent's impressions of gaps in the service
 - Whether services currently respond to people's needs or could be better
 - Why services should be better
 - Gaps in the service
- Enhancement of bereavement care
 - What could be done

- in your service/other services
 - Who's responsibility
 - Who it would benefit
 - How it would help the bereaved older person/ staff in your area
- Introducing new ways of working in the respondent's area
 - Previous experiences
 - What helps
 - What hinders
 - What in particular for a bereavement care strategy
- Other issues respondent would like to raise

APPENDIX 7

Topic guide: bereaved older person interview

Bereavement care for older people

Aims and objectives

The central aims of this study are to explore current service provision for bereaved older people who use NHS services, and to develop a protocol or guidelines for practice that will enable effective case management and communication about bereaved older people across the sectors.

Main objectives of interviewing bereaved relatives is to explore:

- d) people's experiences of being bereaved and the care received in the lead up to the death, at the time of the death and in the days, weeks and months following;
- e) thoughts and opinions about the care they received and the professionals with whom they had contact;
- f) bereaved older people's impressions of gaps in the service and the perceived need for enhancement, ideas for service development.

Introduction

Aim: to introduce the research and set the context for the proceeding discussion.

- Introduce myself and RGU
- Introduce the study: for my PhD, it is about bereavement care for older people
- Information sheet, consent form
- Talk through key points:
 - Purpose of the interview
 - Length of the interview
 - Can stop at any time if you need a break
 - Can come back another day to finish
 - Voluntary nature of participation
 - No questionnaire, more like a conversation
 - Recording of the interview
- Confidentiality and how findings will be reported
- No right or wrong answers, just say what you think
- Any questions

1. Background and personal circumstances

Aim: to introduce the respondent and highlight any key issues about them or their lifestyle that may influence their response to bereavement.

- Daily activities

- Family and contact with them
- Friends and social activities
- General perceptions of health and lifestyle

2. Experience of bereavement support

Aim: to explore the respondent's experiences of contact with health care staff since bereavement.

- The participant's story of experiences they have had (concentrate on the most significant or the most recent)
 - Who was involved, what they did
 - What was said
 - Relationship with staff beforehand
 - interviewee's needs and whether staff were aware
 - whether needs addressed, how, when and by whom or why not
 - individualised care
- Interactions with healthcare staff before the death, at the time of the death, and in the days, weeks and months since
 - Practical support
 - Emotional support
 - Information provision
 - thoughts and opinions about care received
 - impressions of staff involved
 - time - to prepare for the death, with relative at time of death, to speak to staff
 - what was helpful, what was not
- opportunities to speak to staff/ask questions
 - what information was required
 - whether provided, by whom, when
 - provision of required information
 - whether it helped/answered questions
 - if they had to approach someone, describe mechanism and how easy/difficult it was
- passing on information
 - to other healthcare staff
 - awareness of whether this occurred
 - if so, who had been informed and how did you know
 - how did it help?
 - if not, what were the barriers
 - feelings about others being informed
- other services – voluntary sector, counselling, others
 - why, who contacted, how and where
 - experiences
 - beneficial or not

3. Enhancement of services for bereaved older people

Aim: to explore suggestions for how bereavement care might change in the future. What improvements could be made that would assist the grief journey of older people?

- Respondent's impressions of gaps in the service
 - Things that would have made it easier
 - Difficulties for staff
 - Why services should be better
 - Gaps in the service
 - Follow up and communication

- Enhancement of bereavement care
 - What could be done
 - Who's responsibility
 - How it would help
 - What should be in a guideline for staff
 - How would it help?
 - Most important thing that could be done

- Other issues respondent would like to raise

APPENDIX 8A

Example of indexing a transcript (extract)

Its just a case of, we've built up, a lot of the time they've been	12.3
lucky I suppose because people have been here for a period of	
time and we've built up quite a good relationship with their	
relatives. If <u>nae</u> a' the relatives, at least one of them. Somebody	3.1
that's been like maybe the spokes person for the family,	
somebody like that, so I've been quite lucky. But I've always tried	
to like involve them and get their views and all the rest of it and	
we've got the information booklets on what to do after a death,	3.5
ken about going and registering the death and that. I've always	
tried to give folk the information and that and most of the time	10.1
we've found that relatives, well I'd say 75% of the time, we've had	
a good base relationship with the relatives and they've come back	3.1
to see the staff and thank us and a' the rest of it and generally	6.1
most of the time there's a member of staff goes to the funeral.	9.5

Examples of subheadings reflected in the indexing of the interview extract

3.1 Interaction with relatives

3.5 Involving relatives by keeping them informed

6.1 Returning to place of care post bereavement

9.5 Staff going to funeral

10.1 Giving information to the bereaved

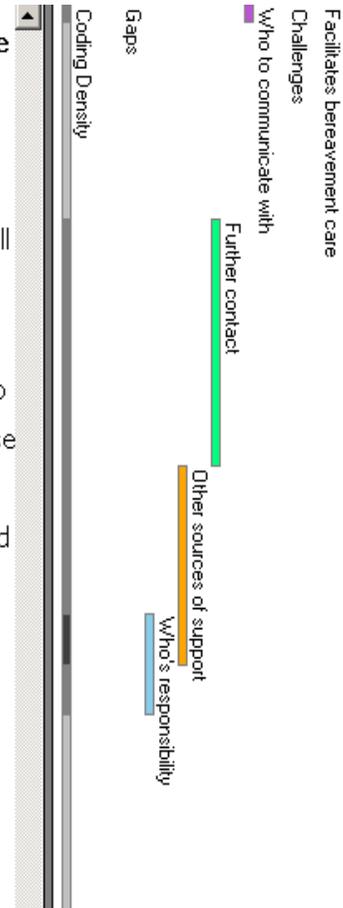
12.3 Relationship between healthcare staff and relatives

APPENDIX 8B

Example of indexing in NVivo 8

AS. Aha. I don't want to keep you much longer. My intention is to develop the draft guideline for bereavement care out of the data that I collect in the interviews. Have you got any ideas of what kind of things you think should be included in a guideline?

C13ST36P OK. I think (pause) its difficult, I don't think we have an overall picture of all the bereaved. We tend to just be involved with the person, people if we've had involvement with their care previous to either the partner's death or been involved with that person's death. I don't think its within the remit of the community nursing team to maybe start seeing patients that we haven't already been involved with. I think because of the time element but I think there does need to be a service locally you know, whether its specifically for bereaved care, you know because there are various clubs and day centres already set up, you know whether its enough to refer onto there but unfortunately sometimes there is a waiting list. Possibly the person that's going to pick up the person that's maybe sitting home with no services is possibly your GP. So there does need to be a service that they can refer onto and whether it is just bringing in all these other services that are already available you know, if its somebody that's maybe not looking after themselves very well, you know not eating you know. Whether the services are there already you know, its getting the person to accept them sometimes.



APPENDIX 8C

Indexing structure for a node (care at the time of the death)

CARE AT THE TIME OF THE DEATH	7.1 Support through established relationships	7.2 Practical tasks	7.3 Family being with deceased	7.4 Interaction with relatives	7.5 Relatives are priority	7.6 Who cares for the bereaved?
C4ST10H hosp Admin		Counter signature when the relatives take the belongings. Forms and leaflets for the relatives, bereavement booklet. Regulations about how long they can keep a body here, just making sure the undertakers ... I'll direct them round, you're never taking a body through the ward in front of people.				
C4ST12H Hosp Sister	If the relatives see you doing your best for their family member they get comfort. They are being treated with dignity and respect although they are maybe comatose. They see that their loved one is being attended to, it gives them reassurance and support.	It helps if they were able to contribute to a comfortable peaceful death for their mum or their dad. That helps them afterwards. Having the last offices is the opportunity to do that final thing for the patient. It's reassuring and gives you closure to the experience as well.	After we've done the last offices and things give the family the opportunity to sit with their spouse and things like that, viewing after death to speak to them, to hold their hand. Just to give them the opportunity to, to say goodbye.			

CARE AT THE TIME OF THE DEATH	7.1 Support through established relationships	7.2 Practical tasks	7.3 Family being with deceased	7.4 Interaction with relatives	7.5 Relatives are priority	7.6 Who cares for the bereaved?
C4ST11H hosp Staff Nurse	<p>We just try to be supportive, we try to build up a relationship with them. Its like daughters and sons more so than like maybe the partner. Its nae that you dinna want to build up a relationship, we do build up a relationship with them but they, you want to take the heart ache away from the partner a wee bit because its like losing half your body to them. A lot of the folk here, they've been married like 60 years. I think they are unconsolable at the time that they just couldn't cope with coming back, but the sons and daughters can. But some folk take it on the chin.</p>			<p>Just try and be supportive, try and encourage them to like speak to one another as well, I think that's really important.</p>	<p>If I was here on the day then they would be the number one priority, as long as naebody, if there was nae burning medical emergencies. If somebody was like very end stages and it was like their relatives are with them, I'd probably spend the majority of my shift going back and fore to them</p>	<p>Some of the nursing assistants that are here are so experienced and they have maybe known the person and the person would maybe rather go and speak to them. Just a good rapport wi' folk, just a good manner. A good wye of communicating. I can think of two, two in particular that just have that extra something, and I particularly like working with them as well.</p>

APPENDIX 8D

Spreadsheet of nodes and codes

Node 1. Bereavement care

Staff need to provide time for supporting bereaved relatives
What's done depends on individual relatives and their needs
There is a reliance on relatives to support each other
Bereavement care is part of the journey with the patient and family
Nursing role with medical staff providing peripheral support
Bereavement care poses active and emotional challenges
What is said and done sticks in people's minds

Node 2. Communication about bereaved relatives

Little communication about bereaved relatives across sectors
Local communication within services
Reliance on family members to support each other
Systematic notification of the death to GPs generally leads to follow up
Little knowledge in other service of what is done with information
Informing GP of the death relieves others of responsibility for relatives
GPs responsible for referral to specialist services

Node 3. Follow up

Variability in bereavement care provided by community staff
Bereavement support offered on the basis of an ongoing relationship with family
Informal/formal assessment of need
Open door
Brief contacts outside of home/hosp – n. home/hospital staff

Node 4. Meaning of bereavement

Particular relationships make bereavement harder
Reality of bereavement dawns in time after funeral.
Bereavement often results in loneliness and social isolation.
Tendency to believe older people take bereavement in their stride.
Complex circumstances tip people into being unable to cope.
Bereavement is a unique experience
Leads to different needs and different ways of coping
Long term, never leaves you
Changing daily routines
It's sad & distressing but most people cope
Losing a very old parent is not necessarily any easier.
Loss of care staff as well
Relief, person not suffering any more
Long time together, not ready to let go
Household management needs
Financial management needs
Emotional needs
Experiences of bereavement that they are taking with them to this
Often there's a feeling of relief
Frailty and vulnerability, existing chronic diseases, reduced mobility makes bereavement harder to cope with
Intensity of grief not always recognised and often misunderstood
Some don't want to carry on living
Older people can have a role in supporting other family members

Node 3. Follow up (cont)

Funeral attendance when appropriate

Bereavement care as unexpected or opportunistic

Providing safe place where can speak about bereavement

Hospital and nursing home staff restricted from following up

Node 5. Preparing relatives

Professional role to prepare relatives

Leads to easier acceptance of the death

Facilitating discussion in families

Honesty re. prognosis

Depends on knowing relative, how much they can cope with

Involve relatives in care decisions

Can't prepare for bereavement reaction

Node 6. Relationship with family

Relationship with family facilitates bereavement care

Community staff in position to support

Bonds with hosp./n. home staff can't continue

Unknown people, with other practice don't get

Node 4. Meaning of bereavement (cont)

Can mean deterioration for those with mental health problems

When not moving on in grief, can experience symptoms

Node 7. Staff concerns

Bereavement care allows staff to close relationship with families

Varied levels of importance given to bereavement care

Need to achieve balance - showing emotion and being in control

When nurses know relatives the right words come naturally

Personal experiences influences what staff do

Staff need time set aside for debriefing and support

Training will not necessarily make people do it well

Experienced staff - mentoring role that supports and encourages

APPENDIX 8E

Example of Wertz (1985) method of phenomenological analysis

Transcript

I had a lady in not that long ago who's grandson had committed suicide and it really had affected her quite badly and she was very upset about it and we just sat and we just spoke. We did this over the space of two or three months and then gradually she just started. She actually, eventually after about two or three months we did decide that she would have antidepressants for a while.

AS. You said you sat and spoke, was it mostly about the grandson?

C5ST13P No, it was in some respects but it was more about how it had affected her. It wasn't necessarily about the grandson, what he had done and what he had achieved and all the rest of it, it was more about well where are we now without him and what's happened and the affect of what's happened on the family. The family's completely changed, and I said 'well has the family really completely changed?' Its just how we feel about it. Well, we took that fairly slowly and it took her a while to sort of see a different way of looking at it and then moving on, and about other members of the family needing her and she just felt that, I think she felt that she failed in some way, you know her family wasn't, wasn't in such a way that everybody was OK and everybody was happy, that actually her family was not like that and in fact one of her grandchildren had committed suicide and I think she was just devastated by that because I think she felt a responsibility to make sure that her family were alright because she was the grandmother and I think that took her a while to come around to changing the way she thought about that. That maybe that wasn't her responsibility to do that and that there was nothing that she could do because she wasn't with everybody all the time. She gradually came to accept it in fact she was in not long ago and she was a lot better. She's off the antidepressants now and she seems to be getting on with things again so...

1. Identification of meaning units

a lady who's grandson had committed suicide
it really had affected her quite badly, was very upset about it
we just sat and we just spoke
We did this over the space of two or three months
then gradually she just started
eventually after about two or three months we did decide that she
would have antidepressants for a while
it was more about how it had affected her
It wasn't necessarily about the grandson
it was more about well where are we now without him
what's happened and the affect of what's happened on the family
The family's completely changed
I said 'well has the family really completely changed?'
Its just how we feel about it

we took that fairly slowly
a while to sort of see a different way of looking at it, then moving on
about other members of the family needing her
she felt that she failed in some way
her family wasn't, wasn't in such a way that everybody was OK and
everybody was happy
her family was not like that, her grandchild had committed suicide
she was just devastated by that
I think she felt a responsibility to make sure that her family were
alright because she was the grandmother
a while to come around, changing the way she thought about it
That maybe that wasn't her responsibility to do that
there was nothing that she could do because she wasn't with
everybody all the time
She gradually came to accept it
she was in not long ago and she was a lot better
She's off the antidepressants now
she seems to be getting on with things again

2. Regrouping

a lady who's grandson had committed suicide
it really had affected her quite badly, was very upset about it
she felt that she failed in some way
her family wasn't, wasn't in such a way that everybody was OK and
everybody was happy
her family was not like that, her grandchild had committed suicide
she was just devastated by that
I think she felt a responsibility to make sure that her family were
alright because she was the grandmother
we just sat and we just spoke
it was more about how it had affected her
It wasn't necessarily about the grandson
it was more about well where are we now without him
what's happened and the affect of what's happened on the family
The family's completely changed
I said 'well has the family really completely changed?'
Its just how we feel about it
We did this over the space of two or three months
eventually after about two or three months we did decide that she
would have antidepressants for a while
we took that fairly slowly
it took her a while to see a different way of looking at it, moving on
about other members of the family needing her
then gradually she just started
took a while to come around, changing the way she thought about it
That maybe that wasn't her responsibility to do that
there was nothing that she could do because she wasn't with
everybody all the time
She gradually came to accept it
she was in not long ago and she was a lot better
She's off the antidepressants now
she seems to be getting on with things again

3. Redescribing

The GP described a female patient who had been coming to see him in the time since her grandson had committed suicide. The suicide had affected her quite badly and she was very upset about it. She felt that she failed in some way because not everyone in her family was happy and comfortable in their lives. She had been forced to acknowledge the reality that there were difficulties in her family and in fact one of her grandchildren had committed suicide. She was devastated by it and felt that she had neglected her responsibility to make sure that her family were alright.

The GP spent time talking about the situation with the patient and discussing how it had affected her rather than necessarily talking about the grandson. They sought to examine what had happened, the affect on the family, and to look at the family dynamics without him. The patient's view was that the family had completely changed, but the GP questioned whether this was really the case or if it was just how it appeared.

Over a period of two or three months the patient came to see the GP regularly to talk about the bereavement issues that had been raised by her grandson's suicide. After this time, and intentionally having taken things slowly, it was decided that she would have antidepressants for a while. The GP said that it had taken her a while to look at things differently and then to find a way to move on. He helped her to appreciate that the other members of the family needed her to support them but he also helped her to see that maybe it wasn't her responsibility to be making sure that everyone was alright and to accept that sometimes there was nothing that she could do because she couldn't be with everybody all the time. She gradually came to accept it and more recently she appeared to be getting on with things again. She was back to see the GP recently and was a lot better and had stopped taking the antidepressants.

4. Points taken into exploration for meaning and interpretation

The sudden loss of grandson –

- affected grandmother profoundly
- caused her to question what she could have done to prevent it
- changed understanding of the family dynamics

Responsibility to her family –

- maintain cohesive relationships
- ensure that no-one was unduly unhappy
- believed she had failed her grandson and others in the family

The GP created a comfortable therapeutic atmosphere –

- grandmother could feel safe to talk
- provided support and treatment
- discussion about how the bereavement had affected her
- focus on how the grandmother could be supported to accept
- focus on how she could support to others in the family
- given time to explore the issues
- anti-depressants in combination with other therapeutic intervention

APPENDIX 9

Topic guide: healthcare staff focus group

Aim

The aim of the focus groups with staff participants is to explore thoughts and opinions about the guideline documents for bereavement care for older people. The findings will be used to edit the documents and produce a finalised version that healthcare staff can adopt in practice.

Main objectives

- to explore initial impressions of the guideline
- look critically at the contents and format of the guideline
- gather suggestions for improvement
- examine how the documents could be used, and how to introduce them to practice

Introduction

Aim: to introduce the research and set the context for the proceeding discussion.

- Introduce myself
- Thank people for coming – time and effort, arrangements for travel expenses, viewing clinical skills unit
- Reason for the research, how it will be used, need for consultation
- Update on the study and progress: aims, interviewing, analysis, guideline development
- Information sheet, consent form
- Talk through key points:
 - Voluntary nature of participation
 - Purpose of the group, ensure all have copies of guidelines
 - Length of the discussion
 - Can leave the room at any time if you need a break
 - Recording
 - Speaking clearly and one at a time
 - Discussion between group members, no need to wait to be asked
 - No right or wrong answers, can agree or disagree with others
 - Don't worry about my feelings, I need to be sure the guidelines are useful for practice and respond to needs of bereaved older people
- Confidentiality and anonymity, how findings will be reported
- Any questions
- Individual introductions – names, roles

- Statement to highlight diversity and point out benefit for contrasting views

1. General thoughts and opinions about the guideline documents

Aim: quickly establish people's initial impressions and feelings about the documents

- General thoughts about guideline documents
- What's good, what's not
- Related to roles, what bits are useful for whom
- What is missing
- Presentation – covers, style, lay out, readability, language, terminology (i.e. care home; relative/family member/bereaved older person; healthcare staff)
- Suggestions for improvements

2. Introductory section (Part A full guideline)

Aim: to explore thoughts and opinions about opening sections

- Background information
 - how useful
 - too little/too much
 - as a supplement to what's known already, what did it add
 - layout
- Guideline development process
- Literature review
- Findings
- Intended outcomes – achievability, relevance

3. Recommendations (Part B)

Aim: to explore usefulness of the recommendations given in the guideline

- The whole
 - order
 - readability
 - use of quotes
- Introductory paragraphs – how useful, length, level of detail
- Organisation (order) – pre bereavement, at time of the death, follow up
- For each recommendation
 - relevance for practice
 - congruity – rationale/recommendation statement

- criteria – which are useful, which are not, suggested additions
- order of criteria
- role of care home staff
- most important issue to address
- relevance of quotes
- suitability for audit
- Opinions about the assessment criteria (Appendix 1)
 - need for assessment
 - how best to assess
 - what to do with information collected
 - relevance of criteria
 - cautions
- Other suggestions for recommendations and relevant criteria

4. Short version of the guideline

Aim: to explore the usefulness of the content and format of the short version of the guideline

- Layout and readability
- Too little/too much
- Introductory page
 - how useful
 - level of detail
- Each separate section (pre bereavement, bereavement care at the time of the death, care after bereavement)
 - how well reflects full guidance
 - what's missing
 - order of criteria
 - relevance for practice
- From each section – what is it most important to address
- Bereavement support information
 - Usefulness of information sources provided
 - What's missing

5. Use of the guidelines in practice

Aim: to explore how the guideline could be used in practice by group members and colleagues

- Willingness to use in practice

- Full version
 - Short version
- Making a difference/change
 - bereavement care practice
 - bereavement journey of older people
- Who would use it
- How it could be used
- How to introduce to practice
- Feasibility of running a follow up project to test the guidelines
 - Explore ideas
- Any other issues to raise

APPENDIX 10

Topic guide: bereaved older people focus group

Aim

The central aim of the focus groups with bereaved older people is to explore thoughts and opinions about the guideline documents. The findings will be used to edit the documents and produce a finalised version that reflects the needs of bereaved older people.

Main objectives

- to explore initial impressions
- look at the contents in terms of how they may improve bereavement experiences
- gather suggestions for amendment/improvement
- examine how the documents could be used by healthcare staff

Introduction

Aim: to introduce the research and set the context for the proceeding discussion.

- Introduce myself
- Thank people for coming – time and effort, arrangements for travel expenses
- Reason for the research, expected outcomes, need for consultation
- Update on the study and progress: aims, interviewing, analysis, guideline development
- Information sheet, consent form
- Talk through key points:
 - Voluntary nature of participation
 - Purpose of the group, ensure all have copies of guidelines
 - Length of the discussion
 - Can leave the room at any time, colleague will accompany
 - Recording
 - Speaking clearly and one at a time
 - Discussion between group members, no need to wait to be asked
 - No right or wrong answers, can agree or disagree with others
 - Don't worry about my feelings, I need to be sure the guidelines are useful for practice and respond to needs of bereaved older people
- Confidentiality and how findings will be reported
- Any questions
- Individual introductions – names

1. General thoughts and opinions about the guideline documents

Aim: quickly establish people's initial impressions and feelings about the documents

- General thoughts about guideline documents

- What's good, what's not
- What bits would have been helpful to them
- What is missing
- Presentation – covers, style, lay out in terms of timeline, lay out of recommendations, readability, language
- Suggestions for improvements

2. Introductory section (referring to full guideline)

Aim: to explore thoughts and opinions about opening sections

- Background information
 - how interesting, what bits were interesting
 - too little/too much
 - layout
- Guideline development process
- Literature review
- Interview analysis
- Intended outcomes
- The whole
 - order
 - readability
 - use of quotes

3. Recommendations

Aim: to explore relevance of the recommendations to experiences of bereavement and bereavement care

- Introductory paragraphs – how useful, length, level of detail
- Organisation – pre bereavement, at time of the death, follow up
- For each recommendation
 - relevance
 - criteria – which are useful, which are not, suggested additions
 - order of criteria
 - most important issue to address
 - relevance of quotes
- Opinions about the assessment criteria and follow up planner
 - need for assessment
 - relevance of criteria
 - what to do with information
 - usefulness of planner
 - cautions
- Other suggestions for recommendations and relevant criteria

4. Short version of the guideline

Aim: to explore the relevance of the content and format of the short version of the guideline

- Layout and readability
- Introductory page
 - Relevance of content for the bereaved
 - level of detail

- Each separate section (pre bereavement, bereavement care at the time of the death, care after bereavement)
 - how well reflects full guidance
 - what's missing
 - order of criteria
 - relevance the bereaved
- From each section – what is most important to address
- Bereavement support information
 - Usefulness of information sources provided
 - Other suggestions

5. Use of the guidelines in practice

Aim: to explore how the guideline could be used in practice for the benefit of bereaved older people

- Making a difference/change
 - bereavement care practice
 - bereavement journey of older people
- Who would use it
- How it could be used
- Feasibility of running a follow up project to test the guidelines
 - Explore ideas
- Any other issues to raise

APPENDIX 11

Questionnaire: CHAIN

CSO (Chief Scientist Office) Research Training Fellow, Audrey Stephen, is currently carrying out a PhD project exploring bereavement care provision for older people. During the project draft guidelines for healthcare staff to use when caring for bereaved older people have been developed.

Click here to see the draft guidelines

- Full version
- Short version

Consultation with healthcare staff on the draft guidelines is ongoing (January 2010). You are invited to provide your thoughts and opinions on the contents of the guidelines by clicking the link below to a short questionnaire. The questionnaire should take no longer than 15 minutes to complete.

Questionnaire

Thank you very much for taking time to review the draft guideline documents, Bereavement Care for Older People. You are invited to provide feedback on the guidelines in the form below. Your thoughts and opinions on the contents of the recommendation statements are particularly appreciated.

When you have completed the questionnaire it will be returned electronically to Audrey Stephen, the researcher. Your responses will remain confidential in accordance with the Data Protection Act (1998) and will be anonymous if used in any reports or outputs of the study. Please provide your comments by 19th February 2010.

Finalised versions of the guideline documents will be available on this website during summer 2010.

The study is funded by the Chief Scientist Office of the Scottish Government Health Directorates.

If you would like more information about the project, please contact Audrey at a.i.stephen@rgu.ac.uk or call +44 (0)1224 263150.

Full version of the draft guideline

1. Please give your opinions on the presentation of the guideline document (full version)

	Very good	good	Satisfactory	Poor	Very poor
Order of sections					
Layout					
Readability					

Part A. Introductory section of full guideline

2. How useful was the information provided in Part A to aid your understanding of bereavement and older people, and the research process undertaken?

	Very useful	Useful	Not useful
Background			
Literature review			
Findings			

Please add any comments you would like to make about Part A. here.

--

Part B. Recommendations

3. It is important that the recommendation criteria in the guideline are reflective of things that can be done by healthcare staff to support older people before their relative's death, at the time of the death, and afterwards. Please indicate below your opinions about the appropriateness of the recommendations, and add your comments.

	Very appropriate	Partially appropriate	Not appropriate
Recommendation 1.1 Create a supportive environment (p13)			
Recommendation 1.2 Prepare the			

older person for the loss (p14)			
Recommendation 2.1.Sensitively break the bad news (p17)			
Please add comments on 1.1-1.3 here			
Recommendation 2.1.Sensitively break the bad news (p17)			
Recommendation 2.2 Respond to immediate support needs (p18)			
Recommendation 2.3 Facilitate ongoing support (p20)			
Recommendation 2.4 Information (p22)			
Please add comments on 2.1 – 2.4 here			
Recommendation 3.1 Plan follow up for the bereaved older person (p25)			
Recommendation 3.2 Bereavement visiting for the older person (p27)			
Recommendation 3.3 Follow up from non community based staff (p29)			
Please add comments on 3.1 – 3.3 here			

Short version of the draft guideline

4. Please indicate your opinions about the short guideline

	Very good	Good	Satisfactory	Poor	Very poor
Layout					
Readability					
contents					

5. Add any comments you would like to make about the short guideline here.

6. Add any other comments you would like to make about the guidelines here.

Information about you

Space is provided here for you to give your name, job title, and place of work. It is up to you whether or not you want to provide this information, however, it would be helpful if you at least give your job title and area of practice e.g. hospital ward; general practice; care home.

Name:

Job title:

Place of practice:

Thank you

Thank you very much for completing the feedback form. Your opinions will be fed into the finalisation of a guideline for use in healthcare practice.

APPENDIX 12

Extract from spreadsheet recording feedback from guideline consultation

FEEDBACK ON GUIDELINE DOCUMENTS

Participant number/name	Date	Means of feedback	Feedback	Decision making	Amendment	Date
#####	####	Personal contact	Very good			
			List of recommendations should be at front as some may only read this	Need to decide whether Part A remains or not, meantime leave list of recommendations where they are.	None	15th February, 2010
			May cause problems with publication i.e. because documents already circulated			
#####	####	Email	Excellent documents			
#####	####	Email	I have read your draught and it was excellent.			
#####	####	Email	it looks very impressive and well thought-through. I think healthcare personnel has a valuable instrument in hands with your work and I am sure they will gain from it. It is very informative and transparent and I reckon it will attract and convince the audience it is developed for. You have such a clear and compact style of writing that takes the reader by the hand so naturally. I also think you covered about everything I could think of. I am sure it will help the bereaved face their difficulties if people around them use the guidelines. will it make a difference for the bereaved. I am sure you are confident about that, and I am surely inclined to follow you that way, but that is not enough of course. So my question is whether you have any plans of eventually testing the efficacy and cost-effectiveness of recommendations?			

#####	####	Email	I have one observation to make re your draft and that is on page 31: Cruse and your wording of "and advice to help them to understand their grief and cope with their loss." Yes Cruse offers counselling and they distribute handouts to clients but we do not see this as offering advice - more offering support. Quite often if people come to counselling on the understanding we will be giving them advice they are disappointed and do not return. I feel we offer support that hopefully will facilitate a good counselling relationship and enable a person to better understand their grief, to work through their grief and better cope with their loss. The leaflet I mentioned has been described to me by clients as supportive because it helps them identify with thoughts/feelings at that time.	Agree. On referring back to interview transcript, she seemed to refer to a leaflet on the Cruse website that is given to those waiting for counselling. There are a variety of leaflets on the website that would be useful, though I can't say which one this was specifically. Cruse website given as a resource in section 4 of the guideline.	Wording changed	15th February, 2010
#####	####	Phone message on answering machine	Guideline pretty much OK. Referred to sudden death as opposed to expected and was in agreement with what I have said about emotions being heightened and more intensive support requirement. Went on to talk about spousally bereaved older men and following them up more closely. Thinks they are likely to have more support needs as loss of wife also means loss of social network. Fears that they become isolated.	Wish to maintain generic nature of the guideline, additional needs of men should be assessed on an individual basis.	None	15th February, 2010
#####	####	Meeting	Initially wondered why it was focused on older people, but she said that on reading through it she decided that it was important that older people and bereavement is highlighted. She thought that the loneliness of bereavement is even worse for older people, particularly those who have lost a life partner.	Guideline was developed through research about and including older people and may not be relevant to other groups. Also believe that the focus should be on older people as this is when bereavement most usually occurs and people are often multiply bereaved.	None	16th February, 2010

			In practice she works with patients mainly in 40s-50s age group. As well as husbands and wives, where the focus of support is, there are also older parents to be considered. The guideline should highlight their needs.	Included in rec. 3.1	None	16th February, 2010
			Wondered about the reality of having someone sitting with a dying patient though she thought it should remain in the guideline because it should happen.	Yes, this may be challenging	Leave in as a goal for best practice	16th February, 2010
#####			Well presented, well pitched, a useful resource for training and holistic.	Possibility for use as a training tool.	Will be considered as subsequent work arising from the project.	
#####	####	CHAIN	Since the rate of suicide in older ment is relatively high and many will have surviving relatives, it may be worth saying a little more about bereavement through suicide (I note that you do cite "Help is at Hand in your useful documents.	The guideline was designed to be generically applied and flexible to different situations. Not sure that I can say anything more specific about suicide without mentioning other scenarios eg. Murder. In fact I haven't said anything specifically about accidental deaths and they would be more common.	No amendment made, wish the guideline to be applicable in all situations where bereavement occurs	
#####			I particularly liked this structure and breakdown - they are very useful guidelines for a range of professionals.	Yes, meant to be used across sectors.	None	
#####	####	CHAIN	Personal accounts feom bereaved individuals very useful in supporting the importance of attending to these needs.	Agree that quotes add to the weight of the recommendations.	None	
#####r	####	CHAIN	An intuitive assessment , backed up by a standard format Assessment Tool, is a very useful addition to what we already offer in terms of support	See E39 above for comment on assessment	None	

