Bereavement and bereavement care: consultation and mapping of practice (phase 2).

STEPHEN, A.I., WIMPENNY, P., UNWIN, R., WORK, F., MACDUFF, C., DEMPSTER, P., WILCOCK, S.E. and BROWN, A.M.
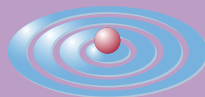
2006

BEREAVEMENT AND BEREAVEMENT CARE
Consultation and Mapping of Practice (Phase 2)

FINAL REPORT

THE JOANNA BRIGGS INSTITUTE

Bereavement and Bereavement Care

Consultation and Mapping of Practice (Phase 2)

Final Report

September 2006

Stephen AI, Wimpenny P, Unwin R, Work F, Macduff C, Dempster P,

Wilcock SE and Brown AM

School of Nursing and Midwifery
The Faculty of Health and Social Care
The Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QG

Contact persons: Audrey Stephen, 01224 263150 or e-mail
a.i.stephen@rgu.ac.uk or Dr Peter Wimpenny, 01224 262650. E-mail:
p.wimpenny@rgu.ac.uk Fax number: 01224 262630.

A summary version of the report is available from the authors.

Acknowledgements

Contents

Figures and Tables

Appendices

Chapter 1: Introduction

Looking for information on bereavement care, other than reading material in professional or academic journals can be a daunting task. A search of the internet provides a significant 1,116,403 hits, which range from general information, through bereavement services (funeral directors, counselling, local authorities etc) to individuals talking about their loss. This is perhaps indicative of the extent to which death and the subsequent bereavement are part of our lives, despite an implicit tendency to hide death, dying and bereavement (Aries 1983). In addition reports related to bereavement appear regularly in the media, the most recent focused on the provision of memorials on hills and mountains and at roadsides following road traffic accidents (Guardian Unlimited 2006).

Whilst it is therefore possible for individuals to get news, information and advice about bereavement in significant quantities, irrespective of appropriateness, it appears that dealing with death, dying and bereavement, particularly within health and social care is increasingly challenging. This in some way may be due, in the UK, to the organ and tissue retention scandals (Kennedy 2001, Redfern et al. 2001). However, engagement and interest in bereavement and bereavement care extends beyond this as it is a universal experience that may impact on health and well-being (Parkes 2001) and as such demands the attention of those working in health and social care. Therefore understanding and developing bereavement services through policy and practice could, it may be argued, have significant benefit. However, how to achieve this, and which aspects to develop are not clear as there is a plethora of perspectives and services, some of which may be competing.

This research sought to engage the perspectives of health and social care practitioners in statutory and voluntary sectors (including education settings), through a consultation and mapping process which drew on the literature review previously undertaken (Wimpenny et al. 2006). The literature review could not capture practitioners' views of bereavement and bereavement care, and what factors may be influencing their practice. Indeed practitioners and others who are working with the bereaved may

view evidence, such as the literature review, as not being the 'real world' (Bridging Working Group 2005). Hence the need to ensure their perspective is checked out and incorporated into work which may inform future evidence-based policy and practice. It may also be the case that practitioners who work with the bereaved are located between the academic perspective (which might dominate a literature review) and the bereaved themselves (McLaren 1998) and therefore have a unique insight into bereavement care.

1.1. Bereavement

This report is focused on mapping and consulting with a range of practitioners in health and social care. In order to provide the initial context, however, it is worth recounting some of the brief introduction to bereavement and bereavement care that appears in the literature review.

The classic work of Lindemann (1994) is often credited as one of the first studies of grief when he followed up the bereaved from the Coconut Grove night club fire. However, Parkes (2001) identifies earlier writing that demonstrates clearly that grief was already a subject of practical and academic interest. The subsequent development of stage or phase models of death and grief provided a perspective on the common processes and allowed many practitioners and others to begin to develop understanding, research and education (Bowlby 1969, Kubler-Ross 1995). Without such models it might be argued that the many developments in bereavement care would not have happened. These models are still reflected throughout the literature, although the stage and phase theories and models have been replaced by ones that reflect grief as an ongoing process of 'continuing bonds' (Klass et al. 1996) and a continual move between loss and restoration (Stroebe and Schut 1999). Such models can be useful to practitioners in guiding their work with the bereaved and giving them confidence in assessing and engaging appropriately (Greenstreet 2004).

There is also evidence of other social and medical models impacting upon practice. According to Rhodes (2001) death is more than a biological act and has sociological and legal/political elements that influence any

bereavement response. In addition there are also spiritual and psychological elements (Heyse-Moore 1996, Worden 1991) and in all cases there are probably policy and training implications (Kasetenbaum 1992, Ross 1997).

Bonnano and Kaltman (2001), in a review of grief and bereavement, identified four common areas of disruption in the first year after bereavement: cognitive disorganisation, dysphoria, health deficits, and disruptions in social and occupational functioning. However, it must be noted that the majority of the bereaved, 90-95%, will 'recover' from their loss within a 'reasonable' time period (Centre for the Advancement of Health 2003, Schut et al. 2001). The definitions of 'recover' (Balk 2004) and 'reasonable' are difficult to specify as it will vary from individual to individual, although some broad time periods (usually six months) have been identified. It may also be the case for some, that recovery actually goes beyond pre loss levels of functioning (Lindstrøm 2002), whilst for others the nominal time period for dealing with grief is over-long or not long enough. Parkes (1972) highlighted such variability in his classic studies of grief. He highlighted the antecedent, concurrent and subsequent factors which may impinge on the outcomes for the bereaved.

The moment of death and subsequent bereavement is one which produces a wide variety of emotional reactions in the bereaved such as sadness, anger, separation distress, denial, loss of interest in self and social functioning, constant replaying of the death and events leading up to it. However, the evidence clearly shows that the presence of such strong feelings and diminution of quality of life does not equate to poor outcomes for the majority of people. Furthermore, it appears difficult to know if the expression or withholding of such strong emotions, influenced by cultural and spiritual factors, at the time of death and beyond is beneficial to the bereaved (Stroebe et al. 2005).

What is also apparent, as Parkes and others have described, is that there are factors which may impact on the outcomes. Some of these factors could be addressed by all types of practitioners in health and social care organisations, education settings, voluntary and community groups and be used to assist in assessment of those most likely to develop physical,

economic, social and mental health problems. There are also circumstances, such as in perinatal bereavement, where the specific contextual factors are also strong mediators of outcomes in addition to the other broader range of factors (Janssen 1996).

1.2. Bereavement Care

Whilst there are a number of definitions of bereavement, including that from Christ et al (2003); 'the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one' (p554), they are hard to find for bereavement care. However, Schut et al (2001) do provide a definition of what the basic idea of bereavement care might be about, ' ..to benefit the bereaved individual, to help him or her to deal with the emotional and practical problems following the loss of a loved one' (p705). There is, as far as we can ascertain, no definition of bereavement care as applied to the delivery of services. As a starting point we have assumed that bereavement care may cover a spectrum of services from informal and formal befriending approaches, to care provided by health and social care practitioners before, at the point of death and beyond, to that provided by mental health practitioners for those who develop complicated grief.

The range of situations leading to bereavement and the health and social care settings in which bereavement care is a feature are possibly infinite. The literature review (Wimpenny et al. 2006) identified those that were readily apparent, including acute and hospital based care, cancer and palliative care, community and primary care, mental health and learning disability services, care of older people, care of children, neonatal and other obstetric care settings and care of families. Specific types of death were also included; those that were traumatic (suicide, murder, disasters and trauma) or from diseases such as HIV/AIDS.

The need for intervention at all if grief is a 'normal' process from which most people will emerge has been questioned (Raphael et al. 2001). In addition the evidence of the effectiveness of interventions is relatively weak (Jordan and Neimeyer 2003). However, there would also appear to be many 'interventions' that relate to bereavement in general:

preventative/preparative type work through education; communication skills for professionals and other practitioners at the time of death and after; social and community support; designated policies and procedures; and roles of volunteers and voluntary groups. These interventions and others are often part of the range of approaches that health and social care practitioners and organisations use to address bereavement care. What they see as important areas for action are at the heart of this study.

Accordingly, determining an appropriate spread of practitioners and organisations to represent the breadth of bereavement care can be problematic, particularly when a significant number may be working in palliative care where bereavement care is an integral part of care provision (Field et al. 2004, Nightingale et al. 1998). The extent to which bereavement care provision is integral to other services is difficult to identify as demand may be hidden or localised. Estimating demand and therefore requisite services, suggests underprovision (The Nucleus Group 2004) although bereavement related issues have been identified as accounting for between 20-50% of primary care counsellors workloads (Payne et al. 2002). This may only represent a small proportion of need within a specific context, i.e. where such services are provided in primary care and for those who get referred.

Counselling and support services, may also develop where there is a locally identified need, in Scotland for example following the Piper Alpha disaster (Hull et al. 2002) or the Dunblane tragedy (Black 1998). However, due to the universal nature of bereavement there is a need for bereavement services to be present across all health and social care settings, particularly as most deaths now occur in hospital.

In 2004 there were 56,187 deaths in Scotland (General Register Office for Scotland 2004). If as The Nucleus Group (2004) identified, each death will have an impact on eight relatives or significant others and 5% (minimum level identified for those who will not adapt) will require further help and support, this suggests that there could be 22,474 people requiring a service of some type. Even if the impact of death is confined to two people per death this would still indicate, at the minimum, 5,618 people who may be in need of some form of service. The extent to which

such people are accessing and using services in Scotland at present is not known. In addition there is no way of determining the extent to which these figures reflect the reality as the range of services on offer and their usage have never been audited or mapped. For the remaining 95% of bereaved there are also potential needs that may not be addressed and which may be of a more informal nature.

There are also, within many settings and types of death, voluntary groups who provide information, advice and support for the bereaved. Such groups are often an integral part of service provision, although the extent to which connections exist between statutory, voluntary and other community services for the bereaved is not known. It may be assumed that in many cases the bereaved have to navigate their own movement across the boundaries between services as they embark on their bereavement journey.

The range of interventions available suggests that no single approach will suit and may only be required by those people who develop 'abnormal' grief or associated anxiety, depression and post traumatic stress disorder. Identifying and targeting these individuals may be a useful strategy (Raphael et al. 2001). If intervention for bereavement is required then an integrative approach appears to be favoured, that is education, psychotherapy and pharmacotherapy provided by a range of agencies.

1.3. The Scottish context

Phase 1 of the study identified thirteen key messages within the literature about bereavement and bereavement care. Whilst these were identified through a systematic review of international literature there was a clear need to find out if these outcomes were relevant to practice in Scotland and to illuminate what services were being provided for the bereaved. The study, reported in the forthcoming pages, was designed to gather perspectives of those who were identified as key providers, educators or researchers. It is clear that bereavement and bereavement care is becoming an increasing priority globally and, as such, there is much to learn from those with experience and expertise, irrespective of context. However, although some national UK and international perspectives were

sought, these were utilised to inform the Scottish context as outlined in The National Framework for Service Change in the NHS in Scotland (Scottish Executive Health Department 2005).

Chapter 2: Study design

A qualitative interview study was designed to gather the perspectives of service providers on bereavement and bereavement care. This was believed to be the most appropriate means of collecting detailed information about people's experiences, and their thoughts and opinions about the key messages from Phase 1. A Bereavement Care Workshop was also an integral part of the study design and was a major forum for data collection.

2.1. Aims and objectives

The aims of Phase 2 were to:

1. map the level of agreement of service providers with the key messages taken from Phase 1, the literature review;
2. describe the level and nature of current practice in bereavement care in Scotland.

Objectives:

1. consult existing contacts from Phase 1 about the key messages from the literature review;
2. describe how bereavement care is delivered by service providers;
3. establish new contacts through mailing and snowball sampling approaches and carry out consultation as in points 1 and 2;
4. gauge interviewees' perceptions of bereavement care priorities;
5. share outcomes of Phase 1 and the consultation and mapping with an invited audience to determine recommendations to be made to Scottish Executive Health Department (SEHD) related to policy and practice.

The project was funded to run for 6 months commencing on 27th February 2006. Table 1 shows the activities undertaken by the project team (see Appendix 1 for project team and steering group membership) within this time frame.

Table 1. Time frame of project

Dates	Activities
27th February – 17th March	Identification of key contacts from Phase 1 Finalising format of invitation letter and consent form Finalising format of interview schedule Obtaining ethical approval
20th March – 2nd June	Telephone interviews with key contacts Identification of snowball and additional contacts Invitations to selected snowball and additional contacts Telephone interviews with snowball and additional contacts Transcription of interview recordings Identification of emerging themes
5th June – 5th July	Familiarisation with transcripts Identification of key themes Identification of quotes from interviews to support themes Amalgamation of data into a briefing paper for workshop delegates
6th July	Bereavement Care Workshop
7th July – 25th August	Amalgamation of data from workshop with interview data Summary report produced Writing of final project report

2.2. Recruitment of interviewees

Recruitment was carried out using three methods:

1. invitations to established contacts;
2. invitations to additional contacts;
3. invitations to snowball contacts.

9

2.2.1. Established contacts

Initial identification of possible interviewees for the study was carried out through selection from contacts established in Phase 1. These contacts were made during a process of identification of grey literature for inclusion in the literature review. Many informants, including NHS staff, clinicians with specialist roles, educationalists, chaplains, voluntary sector providers, funeral directors and researchers from across the UK, had provided information leaflets, policy documents and operational role type materials. The information was examined by the project team and key contacts were selected on the basis of the type of service provided and the level of engagement of the informant in provision of bereavement care. Thirty-eight informants were identified as key contacts who would be invited to participate in an interview for the project. Invitations were extended to key contacts in Scotland and to those in other parts of the UK where there appeared to be sufficient involvement of the service provider in bereavement related work. Prominent academic researchers in bereavement were included at this stage.

2.2.2. Additional contacts

Additional contacts including national associations, for example The National Association of Funeral Directors, were also established through the grey literature. The identification of other additional contacts was carried out throughout the project as a means of filling gaps in data collection from specific areas through a process of purposive sampling (Morse 1989). Initially there was awareness that hospice and palliative care services were established providers of bereavement care. In order to ensure the inclusion of the views of practitioners in these areas the names and addresses of ten hospice medical directors in Scotland were obtained and they were invited to participate. Staff at cancer support centres in Scotland and local funeral directors were also contacted in this way.

The research team were also aware of strategic work being carried out at the Department of Health in England and the equivalents in Wales and Northern Ireland, in the development of bereavement care services. Efforts were made to make contact with the key people at this level as it

was believed that their experiences could inform developments in Scotland at an equivalent level. Some internet searching was also carried out for services relevant to bereavement care. Web forums were used to contact staff in areas with low representation that the team felt would have an important contribution to make, for example, mental health and occupational health services. Members of staff at The Robert Gordon University with an interest in bereavement were identified and a number of contacts were also established through members of the research team providing information about service providers known to them who may have some involvement with bereavement care.

2.2.3. Snowball contacts

An additional approach to recruitment for the interview study was to identify others who may add further perspectives to the illumination of practice. Those interviewed were asked to nominate others in a form of snowball sampling so that those with most engagement with bereavement and bereavement care could be accessed (Blacktop 1996). Potential interviewees were selected from the nominations and invited to participate on the basis that: they were likely to provide a different perspective from those already interviewed; they were from an under-represented group e.g. general practitioners; they were from an under-represented region e.g. Highlands and Islands; or they were thought to have a high level of involvement in bereavement care. Snowball sampling was to be continued until a point was reached when no more new nominations were made by interviewees or when no time remained for further interviews to take place.

2.3. Contacting potential interviewees

The study received ethical approval from the School of Nursing and Midwifery Ethics Review Panel at The Robert Gordon University. Consultation with the local NHS Research Ethics Committee indicated that no formal COREC application would be necessary. However, the need to ensure that participants had adequate information about the project and were allowed to give their prior approval to taking part in a telephone

interview was highlighted. This was addressed with an information sheet, letter of invitation and consent form (see Appendices 2, 3, & 4). An advanced organiser for arrangement of interview appointments was also prepared (Appendix 5).

Invitations were extended to the key contacts and some additional contacts initially, and throughout the period of interviewing invitations were sent to selected snowball contacts and other additional contacts. Invitations containing the aforementioned documentation and a copy of (or web link to) the executive summary of the review (Phase 1) were sent via email to those for whom contact addresses were available and by post to those for whom only postal addresses were available. Invitees were asked to make contact with the research team by email, telephone or post if they were interested in participating in an interview. Following this initial contact, for those who agreed to take part, an appointment was made for a telephone interview to take place on a date and time suitable for the interviewee. In some cases, particularly when postal contact had been made, the advanced organiser was used to aid the process of interview scheduling.

Interviewees were asked to return the signed consent form to the study office prior to the interview taking place. On the same form the level of consent was also obtained for reporting of the results of the study. Interviewees were asked if they would allow the researchers to use their name and that of their organisation in the report or wanted these to be anonymised. It was believed that identification of quotes included in the report of the study might highlight good practice and encourage sharing of ideas between practitioners. As a number of interviewees did not want themselves or their organisations to be identified, this report presents quotes anonymously.

2.4. Data collection

Data collection for Phase 2 was carried out in two separate parts:
1. semi-structured interviewing (consultation and mapping);
2. the bereavement care workshop.

2.4.1. Semi-structured interviewing

Semi-structured interviewing carried out by telephone was the method of choice for the project. This approach was taken for practical reasons and to facilitate collection of data of the best possible quality. Telephone interviewing enabled the research team to contact respondents from a wide geographical spread and to explore bereavement and bereavement care practice within a relatively short time scale. This method could also have greater acceptability to contacts and be equally effective as face to face interviewing in eliciting qualitative data (Barriball and Christian, et al. 1996). The interviews were carried out by four members of the research team (AS, PW, RU, FW). Verbal consent for recording of the interview was obtained from the interviewee prior to commencement. Level of consent for reporting of the results of the study was also rechecked verbally. Recording of the conversation was made using a telephone attachment that either recorded the interviews to an audio cassette via a tape recorder or to a sound file on the hard drive of a laptop computer (Re-Tell Ltd. 2006). Interviews followed a schedule devised for the purpose (Appendix 6) and lasted approximately 40 minutes.

The interview study sought to build on the outcomes of Phase 1 and establish descriptions of practice and how bereavement care may be developed in the future. There were three main sections of the interview:

1. Mapping to key messages from Phase 1

   a) identification of key areas from the review in which interviewee is involved;

   b) identification and prioritisation of key messages from the review for the interviewee;

   c) identification of gaps and closest matches between key messages from the review and actual practice on a national basis.

2. Bereavement care practices

   a) the involvement of the interviewee and their organisation in bereavement;

   b) how the service developed;

   c) how it is used in practice;

   d) its transferability to other areas and settings.

3. Identification of other potential interviewees with involvement in bereavement care (snowball sampling).

Interviews were transcribed from the recorded versions by a member of the research team. An initial attempt, because of time constraints, was made to selectively transcribe only the parts of the interview that were felt to be important. However, this was particularly difficult to carry out and in order to maintain the quality of the data most interviews were transcribed in full. Versions of transcripts were saved as computer files and printed in hard copy to facilitate analysis.

2.4.2. The Bereavement Care Workshop

Further data was collected through participation of the research team at a Bereavement Care Workshop, organised by NHS Education for Scotland, that took place on 6th July 2006 at the Campanile Hotel in Glasgow. The aims of the workshop were to:

1. disseminate the findings of Phase 1 (Systematic Literature Review) and Phase 2 (Consultation and Mapping);
2. explore how the findings of the project to date may shape and influence policy and practice in bereavement care;
3. consider what actions may be necessary to address the challenges for change and improvements in care;
4. meet and network with people from across the system with an interest in bereavement care.

Although it was emphasised that the workshop was not a decision making event it was intended that the outcomes, in addition to the outcomes from Phase 1 and Phase 2 could help to shape future policy and practice. The event took the form of a 'conversational conference' and was led by a trained facilitator. Delegates were informed, in advance of attending the event, that their contributions to the conversations may be used anonymously in the reporting of the research. Their attendance was taken to mean that they were in acknowledgement of this and that they were consenting.

Delegates invited to attend the workshop included:
- o selected interviewees from Phase 2 of the project
- o NHS practitioners – primary and secondary care
- o hospice and palliative care practitioners
- o academic staff – research and teaching
- o voluntary sector providers e.g. Cruse, Alzheimer Scotland
- o local authority service providers
- o procurator fiscal representatives
- o emergency service representatives
- o Scottish Executive representatives
- o NHS QIS representatives
- o NES representatives
- o others

The research team produced a briefing paper that was disseminated to all delegates attending the workshop and was intended to stimulate thinking about bereavement and bereavement care. The paper contained details about the research that had taken place up to the time of the workshop. The initial interpretation and analysis of the data collected for Phase 2 was presented in this document with some questions that had arisen from data analysis to aid discussions on the day.

The workshop took two separate approaches: World Café in the morning and Open Space in the afternoon and was facilitated by Pippa Gough of the King's Fund medical charity (The King's Fund, 2006). A programme for the day can be seen in Appendix 7.

Two questions were discussed over the course of the morning session.

1. When we consider bereavement care policy and practice as it is currently provided in Scotland, what assumptions do we need to test out or challenge? (That is – why do we do things the way we do? Are these the only ways?)
2. What would it take to create change on these issues?

At the Open Space session participants were asked to identify a number of topics emerging from the World Café on which they wanted to do more detailed work. Six areas for action were identified. Meetings were convened at which the topics were discussed in full and decisions taken about how services should be developed to take account of issues of concern.

2.5. Data analysis

Qualitative data analysis of the interview transcripts used the five fold process of Miles and Huberman (1994): familiarisation; identification of themes; indexing; charting and mapping; and interpretation. Interview transcripts were read repeatedly by three members of the research team (AS, PW, RU). Initial emerging themes were identified and these were shared with other members of the team who were also allowed to have access to the transcripts. Consensus was reached between the team members about what the key themes were and this was used to develop a framework for reporting the results of the study. Agreement was also reached about where subthemes fitted within this main framework. Finally quotes were extracted from the transcripts to add quality and richness to the themes and topics identified.

As an additional quality check a random anonymised sample of interview transcripts were analysed using NVivo qualitative analysis software (QSR International 2006) by PD. The object was to perform a process of quality assurance by a researcher who was not directly involved in the collating of data for the second phase. By examining a range of transcripts, independently of the research team, it would be possible to highlight any topics that had been missed or added erroneously by the team. This process would strengthen the conclusions within the final report.

The full transcripts, representing around one fifth of the total interviews conducted, were provided in Word format. These were examined in four phases.

1. all transcripts were read through;
2. transcripts were then edited (headings were added) to allow auto-coding using NVivo;

3. transcripts were 'autocoded' allowing sections of each transcript to be collected together as single documents. Ideas phrases and concepts were coded to nodes that could later be searched;
4. a final examination used various matrix searches and coding was applied.

The process of developing conceptual nodes from a data set is highlighted by Charmaz in Denzin and Lincoln (2003) and also Richards (2005).

Data collected at the Bereavement Care Workshop was collated by the facilitator and passed to the research team. The research team extracted key points and themes from the full report of the day prepared by Pippa Gough. These were written up in full and mapped back to the key overall messages in the literature review (Wimpenny et al 2006) and the themes from the interview study.

Chapter 3: Results

This section of the report details the results of the interview study and the Bereavement Care Workshop. Initially, description is provided of the numbers of interviewees recruited from the three means of recruitment, and some profiling is given for the interviewees recruited (sections 3.1. – 3.3.). The results of the mapping of service providers' opinions to the key messages from Phase 1, the literature review, are described in section 3.4. This section also presents interviewees beliefs about gaps in service provision in Scotland and their priorities for development of bereavement care services. Section 3.5. comprises substantive and detailed information about the nine key themes identified from the interviews, with statements supported by quotations from the interviewees. Finally, the outcomes of discussions between delegates at the Bereavement Care Workshop are described (section 3.6.).

3.1. Recruitment

Contact was made initially with 38 key informants from Phase 1, the literature review. Twenty six letters of invitation were sent by email and 12 posted to those for whom there was no email address. Twenty (53%) of the initial contacts subsequently agreed to participate and were interviewed. The method of contact made no difference to the number recruited, with 50% response rates from each. However, email contact did speed up the process and enabled more interviews to take place in the short time frame available. Thirty-nine additional contacts were identified and invited to participate. The snowballing process identified 70 other possible contacts with involvement in bereavement care. In total 59 people agreed to participate and were interviewed for the study. This was 49.6% of the 119 contacted. Figure 1 is a flow diagram of the recruitment process. Interviewing began on the 20th March and finished on 5th June 2006. The snowballing process had not reached saturation point and could potentially have continued. Interviews lasted an average of 42 minutes each and in total 37.9 hours of data was collected.

Figure 1. Flow diagram of participation

```
┌─────────────────────┐                              ┌─────────────────────┐
│  38 key contacts    │                              │ 39 additional contacts│
│ invited to participate│                            │ invited to participate│
└──────────┬──────────┘                              └──────────┬──────────┘
           │                                                    │
           ▼                                                    ▼
┌─────────────────┐      ┌─────────────────┐      ┌─────────────────────┐
│  20 (53%) key   │....▶ │  70 snowball    │◀.... │ 13   (33%)  additional│
│    contacts     │      │contacts identified│     │ contacts interviewed │
│   interviewed   │      └────────┬────────┘      └──────────┬──────────┘
└────────┬────────┘               │                          │
         │                        ▼                          │
         │               ┌─────────────────┐                 │
         │               │ 42 (100%) snowball│                │
         │               │ contacts invited to│               │
         │               │   participate   │                 │
         │               └────────┬────────┘                 │
         │                        │                          │
         │                        ▼                          │
         │               ┌─────────────────┐                 │
         │               │  26 (62%) snowball│                │
         │               │ contacts interviewed│              │
         │               └────────┬────────┘                 │
         │                        │                          │
         │                        ▼                          │
         │            ┌─────────────────────┐                │
         └───────────▶│ 59 (49.6% of invitees)│◀──────────────┘
                      │   participated in an  │
                      │      interview        │
                      └─────────────────────┘
```
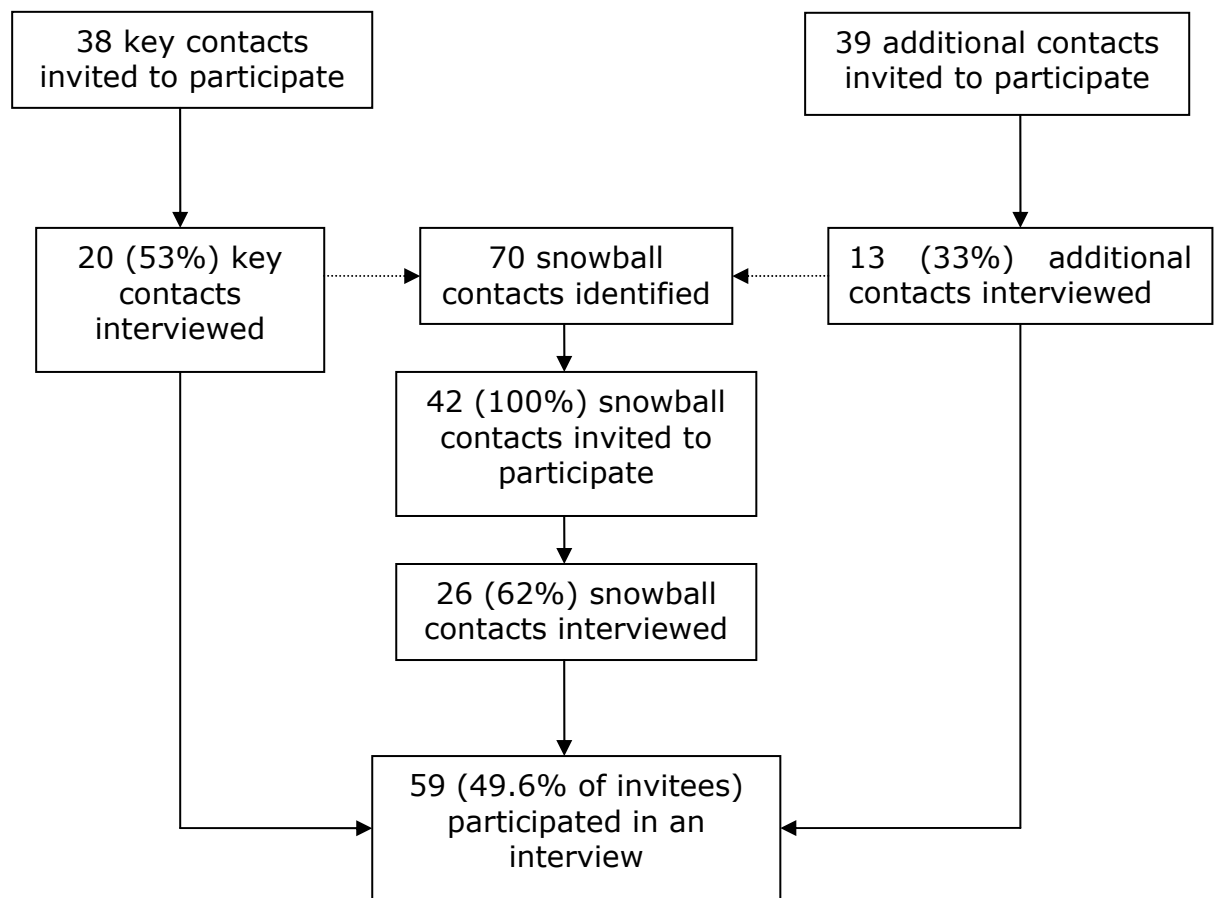
3.2. Field of interest of interviewees

Interviewees came from a variety of fields (Table 2), with palliative care and cancer services being the largest represented group (28.8%). This reflects the findings of the literature review in that services for bereavement care in this area are well developed. Other fields represented were: academic; spiritual care; social work; service providers working with children and young people; neonatal/maternity services; community services; counselling; professional education; funeral directors; acute care hospital; independent sector; mental health; voluntary sector; strategic development. It may appear that some fields of interest are under-represented, for example, spiritual care. This came about in part because some interviewees represent more than one field of interest, for example, two chaplains are also employed in palliative care. They are included in the table under the heading which represents their

main employer. Under-representation was also found in other areas where it was difficult to identify specific contacts, for example, mental health and secondary care medical practitioners. Purposive sampling of hospice medical directors was unsuccessful in recruiting medical staff. However, in most cases the invitation had been passed on to the person within the hospice who had responsibility for bereavement services.

Table 2. Field of interest of interviewees

Field of interest	Number(%) of interviewees
Academic	6 (10.2)
Spiritual care	1 (1.7)
Children/Young People	4 (6.8)
Community	4 (6.8)
Counselling	1 (1.7)
Education	6 (10.2)
Funeral Director	1 (1.7)
Hospital	6 (10.2)
Independent sector	2 (3.4)
Mental Health	1 (1.7)
Palliative care / cancer services	17 (28.8)
Perinatal / neonatal	1 (1.7)
Social work	2 (3.4)
Strategic Development	3 (5.1)
Voluntary sector	4 (6.8)
Total	**59**

Interviewees had a variety of roles within their fields of interest. Palliative care and hospice services provides the best example, see Table 3. Seventeen interviewees were employed in this field and within that there were seven roles represented. Most interviewees were employed as bereavement services co-ordinators, support workers or social workers. These roles appear to be similar across hospices and palliative care settings. Counselling may also be included in these roles. This variation in roles, yet all having an input to bereavement care, demonstrates a theme that runs through the interviews; that bereavement is everybody's business and should not always be the responsibility of specialists.

Table 3. Roles of interviewees employed in palliative care and hospice services

Role	Number
Support worker/bereavement coordinator/social worker	6
Counsellor	2
Chaplain	2
Education	2
Nurse	2
Psychologist	2
Ex-hospice consultant	1
Total	**17**

3.3. Location of interviewees

Fifty of the interviews were carried out with service providers in Scotland. Most regions and major cities are represented (Figure 2 below). The central belt of Scotland, an area located between Dundee to the north and Midlothian and Ayrshire and Arran to the south, provided 32 (54%) interviewees. Areas that may be under represented are Highlands and Islands and Borders, though small numbers of contacts were achieved in these areas. There are larger numbers of interviewees in Aberdeen,

Aberdeenshire and Angus possibly due to the location of the research team and personal contacts of team members.

A wide range of people with involvement in bereavement care took part in the interview study. Efforts were made to contact people who make major contributions to providing appropriate services in their area. The measures taken to identify such people were successful within the time scale available. The range of roles and locations of interviewees were widely spread and where there are low numbers this may reflect low activity in that area. The interview data reported in the next section of this report reflects the opinions of those interviewed and demonstrates the diverse nature of bereavement care.

Figure 2. Location of interviewees
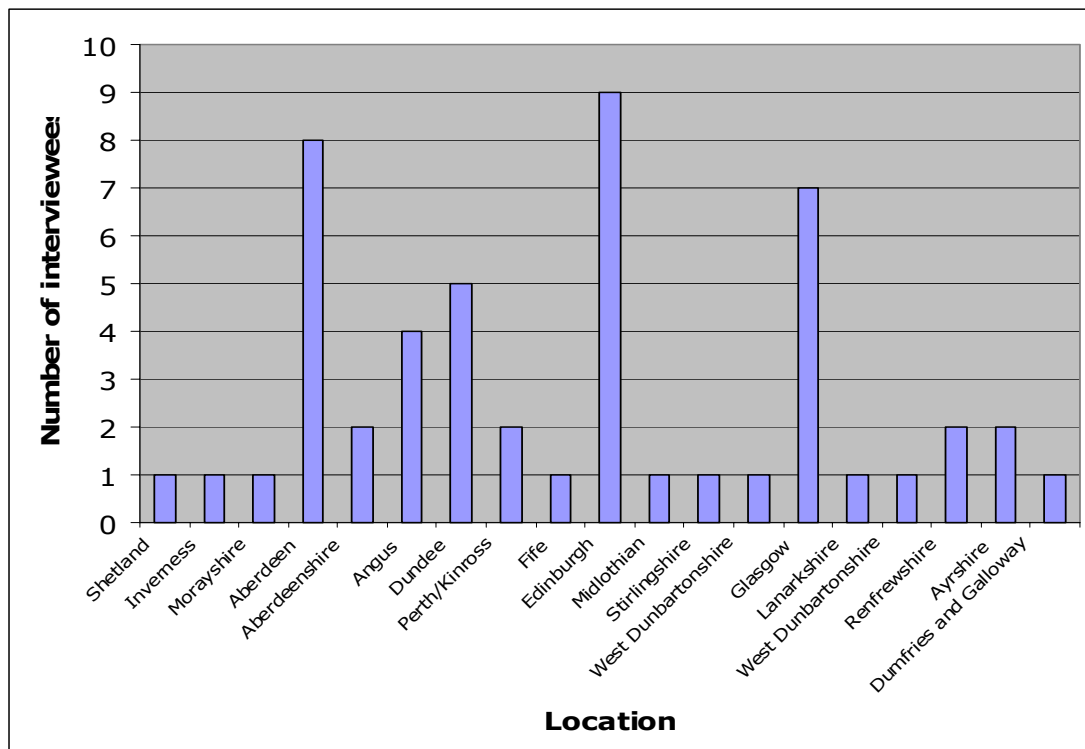
3.4. Mapping to the literature review

During the interviews informants were asked to give their thoughts and opinions about Phase 1 of the study, the Literature Review on Bereavement and Bereavement Care (Wimpenny et al. 2006). This enabled the research team to gauge the level of agreement with the key

outcomes of the review and to assess their validity against actual practice in Scotland.

3.4.1. Areas of involvement

Initially interviewees were asked to identify the areas covered in the review, with which they have involvement, in the course of their work with the bereaved (see Appendix 6). Figure 3 below shows the frequency of occurrence of the main areas of bereavement care in which interviewees said they had involvement.

Figure 3. Areas of interviewees' involvement
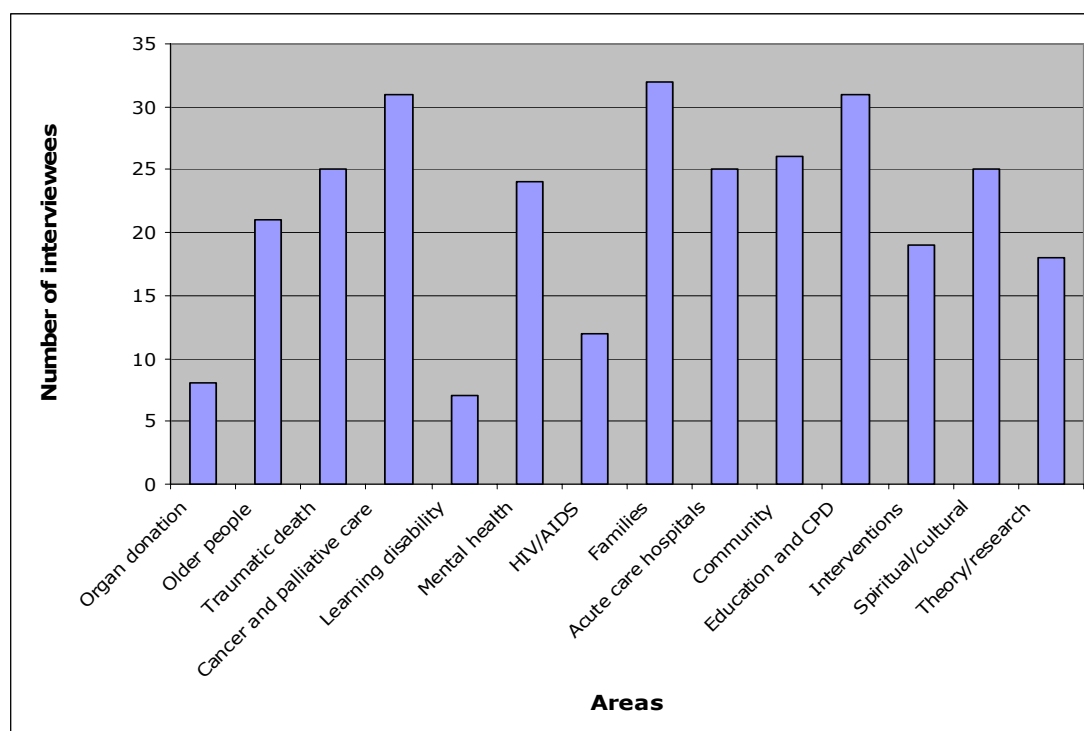
The nature of the roles of many practitioners means that they have involvement in more than one area. Therefore, someone providing bereavement care in a hospice setting may provide support to older people, to children and young people, and be involved with whole families. They may also have a role in education and professional development, spiritual and cultural care and research. The areas of highest involvement were cancer and palliative care, families and education and professional development. This is broadly reflective of some of the main themes

extracted from the interviews (see section 3.5.). Bereavement care in areas related to organ donation, learning disability and HIV/AIDS show lower involvement for the interviewees which may reflect poorly developed services or that the recruitment process did not reach practitioners in these specialised areas. Organ donation was only an area of interest for those involved in strategic development at a national level. Interestingly, 24 respondents said that they were involved with mental health aspects of bereavement care. This contrasts with the low numbers of practitioners in mental health that we were able to recruit to the study. Though some interviewees undoubtedly are involved with mental health issues with their clients, it is unclear what the level of involvement is for the majority.

3.4.2. Mapping to key messages from the review

Interviewees had been given the opportunity to examine the 13 key messages from the literature review prior to the interview. Table 4 gives the 13 key messages and the numbers that had identified each as a priority for their work of that of their organisation. When the numbers were counted they were ranked in the order of those cited as important by most people, rank one signifying the most popular choice.

The top three ranked priorities for bereavement care in Scotland were: the development of education for health and social care professionals; that a compassionate approach should be taken to the bereaved by all involved in their care and that grief should be recognised as being a normal process. Again these are reflected in the main themes extracted from the interviews (see section 3.5.)

Many interviewees commented that all the key messages were priorities and discussed at length how they would like to see developments in many areas taken forward. This provides some validation of the outcomes of the literature review and reassurance that the important aspects of bereavement care highlighted can be reflected in the thoughts and opinions of those in practice in Scotland.

Table 4. Prioritisation of key messages from the review

	Score	Rank
1. Education for health and social care professionals is identified as in need of development.	30	1
2. A compassionate approach to all procedures and processes surrounding death can impact positively on bereavement. The involvement of relatives and families is essential.	29	2
3 Grief is a normal process.	28	3
4 Interventions should be tailored to need. Specific groups of bereaved may require different forms of intervention.	22	4=
5 Cultural and spiritual factors, including issues of stigma need to be incorporated into all areas of bereavement care.	22	4=
6. Risk factors for abnormal responses are amenable to assessment.	21	5
7. Follow-up has been identified as important, particularly by the bereaved.	20	6
8. There are a range of information needs that need to be addressed at local and national levels.	18	7
9. Standards, policies and guidelines for Bereavement Care should be considered in all settings	17	8
10. A co-ordinated approach to bereavement and bereavement care that cuts across statutory and voluntary agencies is required.	14	9=
11. Research into bereavement and bereavement care is particularly difficult but essential in developing services.	14	9=
12. There are 'hidden' socio economic factors, particularly for some groups of bereaved that need to be considered.	11	10=
13. Establishing a *Centre for Bereavement Care* may provide a focal point for developing research, education and practice in Scotland.	11	10=

3.4.3. Areas not covered in the literature review

When asked whether there were any areas of bereavement care that they thought the review did not include, many interviewees (25) said that they thought its contents were very comprehensive and that there were no key

aspects obviously omitted. However, a variety of suggestions were given by other interviewees for areas that they felt were not covered. These included: the burden of bereavement on service and on the health of the bereaved; bereavement as a public health issue; the cultural issues of bereaved asylum seekers; issues of the independent sector; cognitive impairment in the bereaved; social outcomes for bereaved young people; effects of deaths on staff and anticipatory grief.

These areas may, however, be too specialised to include within a broad based review. There may also be a lack of literature in these areas precluding their discussion in any great detail. There can now be a high level of certainty that the contents of the review reflect the main areas of bereavement care in Scotland in the early years of the 21st century. However the rapidly changing nature of society, socially and politically, will mean that ideas about bereavement and bereavement care will develop and change continually. This will demand that research in bereavement and bereavement care is ongoing and the knowledge base is continually updated.

3.4.4. The biggest gaps between the key messages and actual practice in the Scottish national context.

When asked for their opinions about the biggest gaps between the key messages from the review and what actually happens in practice in Scotland, participants often found some difficulty in giving a national perspective. They were aware of what was lacking in their own localities but could not relate to the national situation. Some examples of where people thought that gaps in bereavement care arise nationally are:

- o service provision for the bereaved is poor;
- o grief should not be medicalised;
- o bereavement can have health consequences;
- o there is a need to raise awareness and be much more open about grief as a normal process;
- o education of staff on bereavement needs development;
- o research is required on many bereavement related issues raised;
- o there is a need to develop national policies and guidelines;

- there is no co-ordinated approach to bereavement nationally;
- nobody is taking bereavement seriously;
- follow up of the bereaved is often not available;
- there isn't enough awareness of multicultural issues;
- assessment of risk factors for complicated grief is lacking;
- there is no uniformity in bereavement care across Scotland;
- there is a need for continuity of information, education and support over each area.

These points will be discussed in full within the interview themes (section 3.5.). This enables further validation of the main themes that have emerged from the interview study and stresses their importance for service development in bereavement care. These areas should be of priority to those who are responsible for decision making and policy development at a strategic level.

3.4.5. The closest matches between the key messages and actual practice in the Scottish national context.

When asked where they thought the closest matches were between the key messages from the review and what actually happens in practice, again a number of interviewees felt unable to comment beyond their local situation. However, comments that were made paint a reassuring picture in that considerable bereavement related work has already taken place in certain geographical areas and within some professions. Some examples are that:

- people take a compassionate approach to caring for the bereaved;
- people do work hard to communicate with bereaved families;
- there is recognition that grief is a normal process;
- a range of information is available;
- in specialist facilities people can get extended support;
- interventions are being tailored to need;
- the provision of education for professionals is improving;
- there is increased awareness of the needs of other cultures.

These give some assurance that there is continued development in the services provided to the bereaved and that those aiming to commission new services should not have to start from scratch. There is a variety of approaches to bereavement care already in use and collaboration and sharing of ideas will enable more of the bereaved to have access to the help they require. Though this may be the case, there were some interviewees who were sceptical and did not feel that anything was done particularly well in bereavement care in the Scottish context. This implies that some evaluation of existing services may be timely to assess how well a programme, service or organisation does what it has set out to do, in terms of effectiveness, efficiency and social acceptability (Willcox 1994).

3.5. Analysis of interview data

The completed analysis of the interview data collected found that nine key themes had emerged:

1. The impact of bereavement and bereavement care in Scotland

2. The level of expertise and enthusiasm

3. Equitable service provision

4. Awareness of the impact of grief, loss and bereavement

5. Range and type of approaches to bereavement care

6. Co-ordination and Communication

7. Follow up for the bereaved

8. Guidance

9. Professional educational needs

All key themes have close links with each other as will become apparent in the following nine sections that outline the points raised within each theme.

3.5.1. The impact of bereavement and bereavement care in Scotland

It is difficult to know the full extent to which bereavement and bereavement care impacts on statutory health and social care services and the voluntary sector in Scotland. The time and resources required to

support the bereaved is, at present, largely unknown though this may be vital information for service providers in the planning of future development in their area or for development at a strategic level in Scotland.

It is recognised that bereavement related problems are often first identified in the community, especially within GP practices and health centres and by a variety of professionals.

'Bereavement is a big issue in family care' (GP 1).

'There is a high use of health services by the bereaved; 25% will consult their GP' (Palliative Care Counsellor).

Three practicing GPs were interviewed for the study, two working in rural areas and one in a mixed rural and urban practice. One GP was a lone practitioner while the others were partners in group practices. One had a particular interest in bereavement and dedicated staff time to providing a bereavement service. Perceptions of GPs on the burden of bereavement on their work load varied. All recognised bereavement to be an important issue for their practice though there were concerns about the amount of time bereavement care could take up.

'Time is a constraint for everyone, puts pressure on the professionals. I suspect that most GPs will do bereavement care to some extent. There will be variation depending on whether you are in a rural or urban area' (GP 1).

'We're a small practice, the only one in the village, so time wise it is not a huge impact because the numbers are small, which is quite good because it means that we have the time to spend with people' (GP2).

Personal experience of bereavement may also be a factor that drives development of a dedicated service in primary care rather than the perception of bereavement as a problem in their practice population.

'I kind of made up my mind that if I were ever in a position to have a full time practice of my own that would be an area (bereavement) that I would try to develop in order to support people through, an area that is not an identifiable disease but has long term consequences on health if not managed properly and if they are not supported throughout that period' (GP 3).

Patients may attend their GP with a variety of symptoms that are related to bereavement but that are not immediately attributable, and ultimately may be better addressed through a dedicated service.

'It's almost like you may have a patient coming in with some symptomatology but you lose sight of the fact that they may just be there because of their bereavement. It (the bereavement service) kind of focuses the doctors who are seeing them at that time on the bereavement as being part of the issue that is causing them a difficulty' (GP 3).

If indeed the bereaved are consulting their GPs with bereavement related symptoms but are not being identified through a focused service then there is a need to examine the reasons for this and to clarify what they think the GP can do for them, what the GP is able to provide and whether there is a benefit from their contact with the GP.

'My impression is that there is quite a high variation in the extent to which GPs engage with families. Some local GPs have a very well developed bereavement policy in their practice' (Consultant in Psycho-social Oncology).

Some GPs appear to have more involvement in bereavement care than others and will dedicate more time to it and see it as a greater priority. To enable the bereaved to have positive long term experiences at a time of great distress it seems important that professionals they come into contact with have some awareness of the impact of bereavement.

Interviewees often stressed the importance of providing high quality bereavement care in all sectors (statutory, voluntary, independent) and the need for senior staff to include it in long term planning of services.

'In acute care it is a priority for managers to see it (bereavement care) as important' (Clinical Nurse Specialist 1).

'It is often seen as the responsibility of senior staff but in actual fact it is midwives, medical staff, everyone's business.......... Medical staff are not so interested in something long term that can't be fixed' (University Lecturer).

However, it may be difficult for professionals to recognise that someone may in fact be presenting with a bereavement related problem. This hidden nature of bereavement adds to the difficulty of quantifying the impact of bereavement on primary care staff. Furthermore there appears

to be limited collection of data that would assist determination of the impact.

> 'If a GP has someone who presents with a mass of minor ailments, the start of a chronic illness, minor problems with mental health etc. there seems to be a general acknowledgement that if that GP knows that there has been a significant death in the family they'll put two and two together. But they still tend to treat the ailments and not the cause' (Specialist Health Policy Advisor).
>
> 'It is not the kind of thing where you can say, in NHS Scotland psychological services, that x% of people receiving y therapy it was a bereavement that was identified as a key precipitant, whereas other information systems you can pull out that level of detail' (Consultant in Psycho-social Oncology).

Practitioners in the voluntary sector also talked about the numbers of referrals (from other agencies or self referrals) that they receive for bereavement related difficulties. Some of the voluntary sector providers interviewed were from services dedicated to bereavement, for example Cruse, while others were from services provided for cancer and palliative care or generic counselling services. The quotes below are from managers and counsellors employed in the voluntary sector who discussed the apparently large burden of bereavement on their service:

> 'Out of the people we see (cancer support charity), on average it probably works out at about 25-30% of family members who require additional bereavement support. I feel this is probably in line with other research on the proportion of people who may require additional help' (Head of a cancer support service).
>
> 'On average I get three referrals a week and with me being a single practitioner I can't deal with all the referrals I get' (Voluntary sector practitioner, children and young people).
>
> 'I have been here for 4 years and in that time about a third of the referrals, and indeed about a third of the young people that we have seen have come for counselling for bereavement or loss related issues. I don't know what the annual figure would be but I think somewhere about 250 referrals....a third to a quarter would be bereavement' (Youth Counsellor).
>
> 'Cruse has 28 teams in Scotland, some large with their own premises and paid staff, others are small. There are 5-600 volunteers who receive 13,000 calls per year and give 50,000 hrs of service' (Cruse Bereavement Care Scotland).

Although Cruse provide a service to large numbers of the bereaved there are areas in Scotland that cannot sustain a service due to a variety of factors and possibly illustrating different levels of need in different communities.

'We lost the support of CRUSE. They disbanded, they had been here for a number of years but found that they didn't have sufficient numbers to justify it continuing' (Macmillan Nurse).

This quote from an island practitioner may also suggest that island communities support their bereaved better, negating the need for a dedicated bereavement service.

The apparent lack of formal data collection processes across the sectors for gathering information about the bereaved, the prevalence of bereavement related problems and interventions provided appears to be hampering efforts to quantify the burden. Very few interviewees described the statistics that they collect about their service, although this was not a direct line of questioning taken in the interview. Practitioners from the voluntary sector were more likely to give information about data collection as it may be of particular importance for evaluation and reporting purposes.

'The referral information is taken on a form that I have developed so that I can get stats on the age and gender of the bereaved individual; who their carers are; who it was that died; what was the mode of death; when they died. I've also got a spectrum that I use in terms of trauma, so for example, did the child witness the death; what was their experience of the death – was it unexpected, sudden or were they well prepared, present or not present' (Voluntary sector practitioner, children and young people).

Some NHS professionals have described service audits which may collect data relevant to the prevalence of bereavement related difficulties and the level of service provided, though it appears that care should be exercised in interpreting these figures.

'Our last audit 2004-2005 found that 60% of referrals are pre-bereavement. Sometimes if we do a bit of work before the death that is sufficient and people don't need follow through, other times they need a lot. A percentage of referrals

Staff with involvement in bereavement should now be thinking about the information they record about their service and how it can be used in quantification of the burden of bereavement in Scotland. Collection of appropriate data at the time of death recording could also be useful in terms of identification of the bereaved and the situation of the bereavement.

This interview study has also revealed variations in the range and type of support available within each specialty area, for example, caring for bereaved children within and between geographical areas, between health and social care providers and the voluntary sector. It may be that the services available in a local area only deal with a small proportion of the burden of bereavement or type of need in that area i.e. cancer and palliative care based services, children and adolescent services, a service to carers of people with Alzheimer's disease. The bereaved person may not fit the criteria for any service in their area. The type of provision appears to vary between areas with some having more provision of bereavement care through statutory services and others having higher dependence on the voluntary sector for this type of intervention. This ad hoc service provision and possible proportion of unmet need in a community makes estimation of the burden of bereavement on services very difficult.

'There is no specific bereavement care service' (Social Care Team Leader).

'In our area there is considerable inequity in bereavement service provision. If you are known to the palliative care team before the death you have access to an established service' (Children and Family Support Worker).

'There is only bereavement support for relatives of patients known to the hospices' (Project Manager, non-malignant palliative care).

Inequity of service provision is discussed further in section 3.5.3 of this report.

A further aspect of the burden of bereavement on services is the use of staff time to deal with complaints regarding the experiences of relatives. A large volume of complaints, especially in hospital settings, are from bereaved relatives who have been displeased with the service received when a relative died in the care of the establishment. Poor, or absent, bereavement support before, during and after the death are often sources of grievance. This is not related to specific cases of failure such as that identified at Bristol and Alder Hey for paediatric cardiac surgery and organ retention, but rather to general communication issues between professionals and relatives.

'Most complaints in hospital come through misunderstandings, 50% related to bereavement' (Practice Educator 1).

'We see so many tragic cases in our casework and most of the complaints, over 80%, that I've seen over the years have come from bereavement related issues where someone hasn't been dealt with correctly' (Chief Executive, national voluntary organisation).

'We're told that where there's poor bereavement services, the number of complaints increases' (Policy Officer).

'...hospital care does seem to be an area where this (bereavement care services) needs to be directed... some families' experience of the hospital setting have not been a good one...and didn't deliver the care that the family needed at the time' (Deputy Director of Secondary Care).

'Certainly any problems that we have had, maybe people with prolonged grief and unhappiness, it has been because of things that have happened in the hospital' (GP 2).

Service providers also recognise that getting their part of the service right, whether at the time of the death or later on whilst arranging the funeral, was important to the whole experience of grief and bereavement for the bereaved person and would lessen the need for further use of services. Communication is identified as an important part of good bereavement care.

'If somebody had actually said to them 'I'm really sorry' and spent 20 minutes explaining to them why their loved one had died, the complaint wouldn't have gone anywhere. Its just that mistaken route of where they have taken something because they don't know how to deal with their grief. If somebody was skilled enough to pick that up... The amount of times I have got cross with independent review panels because the NHS has to pay out £10,000 because they didn't take the time to talk to somebody and the poor person has become quite sick because of it' (Chief Executive, national voluntary organisation).

Based on the above messages from practitioners it appears that the burden of bereavement on services in Scotland could be considerable. Many of the bereaved may suffer mental and physical morbidity in the years following bereavement. The lack of research and suitable data on the bereaved means that there is no clear estimate of the impact of bereavement on the workload of health and social care staff across the sectors. Interviewees recognise the importance of bereavement care for the bereaved person and have expressed a desire to develop services that will meet the needs of the individual. There is a need to systematically gauge the level of bereavement related difficulties experienced by the Scottish population and the consequent impact on services in order to direct future service development.

3.5.2. The level of expertise and enthusiasm

A key feature of many interviews was a strong desire to improve bereavement care. There is no doubt that there is considerable expertise and knowledge and a number of enthusiasts spread across the sectors who champion the bereaved and bereavement care. Services have, therefore, often been driven forward as a result of the enthusiasm or personal experience of individual persons or practitioners. This enthusiasm came across clearly in the interviews as practitioners often

35

spoke at length and in detail about the service they provide and seemed central to its development.

> 'It is about the individual in a particular place at a particular time who has a particular vision of what they think should be provided' (Children and Family Support Worker).
>
> 'What I have found with Choose Life[1] and the people who are involved in it is that they are people who have a passion for it and a real drive to achieve things often for their own personal reasons, you know a personal experience of suicide, so I have found that it has been a particular emphasis on that and that in itself has helped to drive change locally and made a big, big difference' (Co-ordinator, Government Programme).

In other parts of the UK specialist bereavement care co-ordinator posts have been created in health authorities as a particular response to the Bristol and Alder Hey enquiries. Interviewees suggested that the success of such posts would depend on the ability of the individual to drive the service ahead.

> 'It comes down to a lot of individuals and where you have a good individual heading up a service in a hospital, then that particular hospital is going to deliver a better service' (Deputy Director of Secondary Care).
>
> 'It's the passionate interest as much as anything else. I think a lot of bereavement care at the front end is driven by the efforts of individual enthusiasts and I try and nurture that flame' (Specialist Health Policy Advisor).

In the NHS in Scotland this type of role is not well developed and only one bereavement co-ordinator was identified for interview. Again her enthusiasm for her work and commitment to championing the cause of the bereaved was evident. She described the development of a comprehensive service within one University Hospital that, though in its early days, may become a model for other areas.

---

[1] Scottish Executive Health Department (2002) Choose Life: A National Strategy and Action Plan to Prevent Suicide in Scotland. Available from: http://www.scotland.gov.uk/Publications/2002/12/15873/14466 [Accessed 09/29 2006]

'My post as bereavement co-ordinator was set up back in April 2005 following a review of various operational but also supportive aspects of bereavement care within our hospitals. What I have responsibility for doing is tackling some of the issues that have arisen and then also developing a project outlining what sort of permanent bereavement centre we need within our hospitals division. The model here is based on what is done in England and I think it will work very well here and it can work elsewhere in the NHS in Scotland' (Bereavement Co-ordinator 1, hospital).

Some practitioners spoke of their enthusiasm and expertise in bereavement care but expressed concern that it is often staff, especially in hospital settings, who are faced with death and the bereaved regularly as part of their work and are under confident and feel unsupported in this respect. Staff training and support was seen as essential in nurturing them to use the skills that they already have to provide the best possible quality of bereavement support to relatives.

'There is a huge gap in the health service in supporting our staff through death (of a patient). If they are not supported, how then can they support relatives in beginning to come to terms with it?' (Clinical Governance Co-ordinator).

In general interviewees felt that health and social care professionals already have the requisite skills to care sensitively for the bereaved but need confidence and the backing of their organisations to develop and have a positive impact on the experiences of relatives. They also recognised the positive impact on the bereaved person of having the support of someone who appears to have a natural ability to communicate well in times of high emotion.

'I think most people do their best within resources, including time. A good carer who relates to the person, is truly with them, even when the person has had a particularly bad experience usually means that the person does not view it totally negatively' (University Lecturer 1).

'...there are individuals that are outstanding and have this emotional intelligence...there are people out there with outstanding skills who aren't necessarily in these posts (bereavement related)' (Head of Midwifery Education).

Whilst this should be viewed positively there is perhaps some caution in that the level of specialisation built up may detract from the need to

ensure that everyone, particularly in health and social care settings, is involved in bereavement care. Some practitioners warned against a reliance on specialised services for bereavement care and see bereavement work as a shared responsibility between sectors and part of the role of all who come into contact with the bereaved.

'I would like to see generic counselling services coming in dealing with bereavement, and that is where training comes in as well, so that a trained counsellor is able to work with bereavement as well. Rather than setting up different services I think that there should be a cross over, that doesn't mean that there shouldn't be specific bereavement services but I think that often if there isn't a specific bereavement service in a particular area maybe the impression given is that there is no help available but there might well be if people are skilled and able to work with bereavement in a more generic way' (Co-ordinator, Government Programme).

'We need to despecialise bereavement care, it's something that everyone is involved in' (Head of Midwifery Education).

'There are lots of practitioners where bereavement work is an aspect of their role but it not their full time job' (Chairperson, bereavement working group).

However, there is no doubt that the range of specialist services for the bereaved, predominately in the voluntary sector, provide committed and valuable support. Examples of this are found in the areas of perinatal death, loss of a child, bereaved children, suicide, and Alzheimer's disease, amongst others.

A specialist model of bereavement care has also developed in many palliative care hospices in Scotland. Practitioners have said that this may be transferable, in whole or in part, to other areas of service provision i.e. acute care hospitals. A full assessment of need within the hospital would be necessary if the palliative care model of bereavement care was to be adopted. Managers would need to ensure its feasibility on a much larger scale and within a more diverse range of specialities.

'It would be lovely (hospice approach) if it could be used in hospitals but the time and other restraints are so much different and I don't think they even have people employed to do bereavement work' (Patient and Family Support Person, hospice).

> 'It may be difficult to transfer the hospice service to a hospital setting as it may become too general as people have different losses. The other side is that people may be glad to know that someone cares enough to invite them back and offer that service' (Hospice Chaplain 1).

Clearly, interviewees want a balance between general and specialist bereavement care services across the sectors. There is a need to make the best use possible of the experience and knowledge of enthusiasts and to develop the existing skills of those whose work includes bereavement care. The challenge is to determine the best way to achieve this with available resources for the benefit of the bereaved.

3.5.3. Equitable service provision

A major factor highlighted by interviewees relates to the level of bereavement support available and the difference between that provided to relatives of those who have died in palliative care and other forms of death. Palliative care, it would appear, is often synonymous with integral bereavement services, support and education and perhaps better communication across health and social care sectors. This was also evident in the number of interviewees who worked in this area and the range of snowball contacts obtained (28.8% of interviewees).

It would appear that, on the whole, palliative care services (hospice and community based) provide a degree of follow up for the bereaved which is not seen from other services. Interviewees within palliative care and in other types of service provision, recognise the exclusive nature of the service delivered by palliative care teams and expressed awareness and concern about the lack of bereavement support for people who have suffered a loss in other circumstances. Hospice staff may be in a good position to develop skills in bereavement care whereas others provide bereavement care on a less regular basis where there may be less need for a specialised service.

> 'If you have cancer you are sorted' (Hospice Chaplain 2).
>
> 'In our area there is considerable inequity in bereavement service provision. If you are known to palliative care before the death then you have access to an established service' (Children and Family Support Worker).

> 'There is only bereavement support for relatives of patients known to the hospices' (Project Manager, non-malignant palliative care).
>
> 'The service is exclusively targeted at those in the (cancer care provider) sphere. We don't have the capacity either logistically or the number of staff or volunteers to expand' (Chaplain, hospice 1).
>
> 'There is a link that seems to be made between palliative care and bereavement and sometimes I think that assumption means that there are quite a significant number of bereaved people missing the sort of support we would hope for because they are not seen by palliative care teams, although it might be argued that everybody needs palliation at end of life. We hope for a process of education that would begin to ask these questions about this and why we have such links between palliative care and bereavement and the terms used interchangeably' (Bereavement Services Manager, hospital).

Information from an established overseas centre for grief and bereavement added to the link between palliative care and bereavement.

> 'With the increasingly aged population and an increased funding focus on palliative care, the Centre was established to support palliative care services throughout the State. Our funding from government comes through palliative care rather than mental health programs. We had a number of strong advocates in government which facilitated the process of establishment' (Director, Centre for Grief and Bereavement).

Interestingly, the lack of funding for bereavement provided by mental health services may be mirrored here in Scotland. There could be a variety of reasons for this, one of which may be the limited engagement of mental health professionals until someone develops complicated grief. Bereavement may also be included within a wider diagnosis of depression, or bereavement care only provided within mental health services for those with existing mental health conditions who are bereaved. Bereavement may not be seen as a priority for any mental health service in its own right. Despite targeted approaches with mental health professionals in this study recruitment was poor and our ability to explore this more fully was reduced.

Although transfer of the model for bereavement care used commonly in palliative care settings was questioned, it is well developed and could be a model for provision in other settings.

'Hospice service approach could be transferred to acute settings such as ICU and A&E (as many people die in A&E as in hospice)' (Researcher 1).

Often hospices are in a position to work closely with members of the family before the death has occurred which may provide the basis for a continuing relationship. Palliative care providers believe that some work with families at this stage is a major factor in enabling uncomplicated grieving and bereavement.

'Pre bereavement support and anticipating grief reaction often negates the need for later input' (Palliative Care Counsellor).

'Our last audit 2004-2005 found that 60% of referrals are pre-bereavement. Sometimes if we do a bit of work before the death that is sufficient and people don't need follow through, other times they need a lot' (Children and Family Support Worker).

In other settings this kind of preparation work may not be possible i.e. for the ambulance paramedic attending the scene of a sudden death, or in A&E and ICU. How far such provision can be transferred to all health care settings is a point worthy of further discussion. However, even in palliative care circles there is some questioning of the extent to which the approach is comprehensive.

'In hospice care bereavement services have been organised although caring for the family as well as the patient is more rhetorical than reality' (Researcher 1).

It may not therefore be a panacea for bereavement care. However, the impression is that there are already pockets of work in, for example intensive care units, primary care, and the independent sector that seek to mirror the palliative care approach, including follow up. There is also a willingness of palliative care practitioners to reach out to other situations through providing some form of service or education package.

'We have a full service of a year post bereavement following a stay in intensive care' (Clinical Nurse Specialist 2).

'What we have in the surgery is myself, district nurse, senior district nurse and one of the admin staff that run, what we call a bereavement protocol' (GP 3).

'I do a lot of follow up. Relatives become friends, they are not just visitors to the nursing home. They don't lose their connection with us and that means that we keep very close contact with folk. I always phone them, visit them weeks after the death. I help them through the initial bereavement and grief' (Nursing Home Manager).

There may also be differences in provision between, for example, urban and rural settings and between provision for particular groups that need to be addressed.

'In the community there are pockets of good practice from district nurses, health visitors and some GPs' (Cruse Bereavement Care Scotland).

'Looking at Scotland there are more services in urban areas, including counselling services – they are often oversubscribed and have waiting lists. I don't think that people who have been bereaved by suicide or other means can wait for that' (Co-ordinator, government programme).

'There can be transport difficulties certainly after bereavement (access to counselling etc. in rural areas)' (GP 2).

Particularly in the voluntary sector, inequities arise due to the funding structure and services are restricted to geographical areas that have provided funding. Even within cancer services geographical inequality has been described where areas to be covered are extremely large or remote.

'Here in (area) I can't get funding from health. I'm funded through Scottish Executive money for (city) but I can't go out to (surrounding areas) because health haven't contributed to the pot' (Voluntary Sector Practitioner).

'We get enquiries from other areas...that we can't offer a service to...It would appear that people from other areas are feeling that there is not a similar service available' (Youth Counsellor).

'There is no uniformity across Scotland; there are pockets of very good practice' (Practice Educator 1).

'Because I cover the whole of the west of Scotland I think that the service that people get offered isn't as equitable as maybe it should be. Realistically if the family live in (city) I can offer them quite regular support, if they live in (area) or

down in (area) then I'm not going to be visiting them once a week so I am going to do more telephone support' (Senior Social Worker, Hospice).

Social class and deprivation were also recognised as major sources of inequality in people's ability to access services. Interviewees provided few suggestions as to how the needs of people in the lower social classes, who least often ask for help from health and social services, can be addressed. There is a suggestion that research in this area is required to determine the extent and nature of the relationship between bereavement and deprivation.

'I think it's easier for middle class to access these things (support), more difficult for others' (Support Worker for Children and Young People, cancer support centre).

'What we are not hearing is the voices of the people who are most likely to be bereaved (perinatally), people from social classes 4 and 5 who tend not to access user groups and also parents who come from ethnic minority groups' (Head of Midwifery Education).

'We must find a way of getting the hidden more transparent....there is work to be done with regard to people in poverty' (Children and Family Support Worker).

'The relationship between bereavement and deprivation has never been considered yet as there is so much bias in terms of community regeneration funding' (Chairperson, bereavement working group).

A general awareness also exists of the need to make bereavement services appropriate to the individual, despite the potential diversity.

'I think there are a lot of judgements made about how we should and shouldn't grieve rather than acknowledging the diversity of how we do it, and it's more diverse than ever it was' (Psychologist, hospice).

Additionally, awareness of culturally sensitive care, which often challenges existing provision.

'It is important to understand the different cultural issues at the end of life and going out to groups and finding out about their requirements and explaining some of the difficulties in hospital' (Bereavement Care Manager, hospital).

'A lot of areas are good at now having timely intervention with families with different cultural needs but few adhere to some of the sensitivities in relation to

bathing or whether they want a post mortem or not. There is a lot more that could be done in those areas' (Chief Executive, national voluntary organisation).

'It is still the case that there are a smaller number of people from ethnic minority groups using the service than we would expect and we are not entirely sure why that it is' (Children and Family Support Worker).

'Asylum seekers, there are about 60 different nationalities in (city). There are sometimes issues like female genital mutilation arising. Language barriers, the immediate and extended family support is not there. There are good culturally sensitive and aware midwife teams in (city), but with so many nationalities it is not possible to know everything about them. Being sensitive and aware, and not putting your own values on someone else are important' (University Lecturer 1).

There is also awareness of spiritual needs with identification of approaches being undertaken that are multi-faith orientated, particularly in health care settings and chaplaincy.

'Things like changing chapels of rest with crosses into non-denominational, actively inclusive areas for people' (Bereavement Co-ordinator 1, hospital).

'The time of remembrance is held three times a year in a secular room in the hospice. Christian services are held in it but it also has articles for other faiths as well' (Psychologist, hospice).

'I offer and approve of an all encompassing tolerant approach, not religious platitudes, being with the family and listening are key to this' (Parish Minister).

'The families we work with come from all religious background and none. Most of them seek some sort of spiritual understanding of the bereavement process. It's not just totally the remit of the chaplains to deal with that, we are all engaged with helping families deal with some of those issues' (Senior Social Worker, hospice).

The following quote highlights the potential lack of service provision specifically aimed at the elderly, who will, as this researcher points out, be the majority of those affected by bereavement and will often be multiply bereaved.

'Incongruous that we are creating services for children and yet not for older people, which is when the majority of people die' (Researcher 1).

It would therefore appear that service provision for bereavement care is not equitable, although practitioners appear to be aware of the constraints. Practitioners are aware of the gaps and inequalities in service provision across Scotland and are beginning to identify areas for improvement. Sharing knowledge, experiences and ideas is vital to the development of high quality bereavement services for all who have a need. However, the type of service available seems often to be bound by geographical location or classification of disease at death rather than the needs of the bereaved.

3.5.4. Awareness of the impact of grief, loss and bereavement

The need to recognise that grief, loss and bereavement are 'normal' processes that everyone will experience is an important and consistent message coming from this interview study and cutting across practice, research and education. There is a tendency for those involved in health care, possibly more so than the general public, to pathologise bereavement and to see it as a problem that can be addressed by health care practitioners and others.

'Joe Public are aware of grief as normal but medical people often forget that. Out of their own environment we take away people's coping strategies. We need to look at normal coping. People are often labelled as having abnormal grief but that is normal for them' (Clinical Nurse Specialist 1).

Practitioners believe that there is a need for a better understanding of the nature of grief and bereavement as part of life. They also wish to highlight the fact that most people are able to work their own way through grief and to adapt to life without the person who has died.

'There is probably a greater need for normalisation of behavioural and emotional responses after death and not pathologising grief' (Consultant in Psycho-social Oncology).

'I think we just need to change the awareness around it because people do die. There is a risk of upsetting people, but its part of life. We are in danger of clinicalising it too much. European countries deal with it very differently and the fact that we almost pretend that it doesn't happen makes the impact far worse' (Chief Executive, national voluntary organisation).

> 'We are keen to promote mental health and wellbeing across the board – also that message should go that people can and do recover from bereavement. That it's a process, its normal that people go through it, that there's a pacing of it even under the most horrendous circumstances that you can think of' (Co-ordinator, government programme).

However, there is an opinion that a culture has arisen where social norms make it difficult for people to cope with grief as a normal process, both in themselves and in others. People are now protected from involvement with death, dying and the bereaved and with this limited experience are less able to accept their loss and more likely to consider their grief 'abnormal' and in need of treatment.

> 'We live in a society where people aren't able to model their grief – we don't have the body at home, in the street, memories of childhood losses' (Chaplain, hospice 1).
>
> 'In some cultures particularly where death is very commonplace there's a great deal of matter of factness about it but here any death is either a tragedy or a scandal and I do worry about us treating death as exceptional' (Head of Midwifery Education).
>
> 'There is a lack of understanding round the whole process, people are almost frightened of it' (Clinical Governance Co-ordinator).

Professionals involved with caring for dying people see a natural progression of their role to be in caring for the bereaved, but there may be a danger of thinking that people can be helped to feel better when this isn't necessarily the case.

> 'Does help help?' (Researcher 2).

Often the only intervention required by the bereaved is for someone to validate the range of feelings that they are experiencing to enable them to adapt. A bereaved person may have a range of feelings that they are finding difficult to accept and contact with a professional who is able to validate these emotions as normal often allows them to move on through their grief.

'Really important to acknowledge that grief is a normal process, that they are not going mad, it is normal' (Support Worker for Children and Young People, cancer support centre).

'A lot of people need reassurance that they are normal. A lot of people need permission to grieve' (Funeral Director).

'One of the commonest things we hear is: I'm glad I've come because I thought I was going mad' (Patient and Family Support Person, hospice).

'I get calls from GPs about parents' grief reaction and I'm able to say: well that sounds fine to me, completely normal for how this family copes and the way they work things out' (Clinical Nurse Specialist).

'One of the most common things that we say on the helpline is when people say: I think I'm going mental, I think I'm going mad. For someone to actually validate what they are feeling, that it is a normal process...this is fine to feel like this, it's OK and its perfectly normal. Just taking 5 minutes to say: its OK to cry, its OK to feel angry, its OK to have these feelings' (Chief Executive, national voluntary organisation).

However, one interviewee points out that it can be difficult to differentiate between normal and abnormal responses as each person will respond differently and in some cases the responses may be influenced by other factors.

'I think it is extremely difficult to define what is abnormal unless you're looking at something like suicide and then it may be another life crisis rather than a complicated grief in itself' (Psychologist, hospice).

In order to encourage the normality of the grieving process many services, for example Cruse, operate a 'reach-in' system whereby the bereaved approach them for help.

'We operate as an in-reach service, based on research which shows better outcomes when the client reaches into services' (Cruse Bereavement Care Scotland).

The service does not accept referrals from other health or social care professionals. This means that people only access the support of this service when they have recognised their own need for help. In many cases this may be a need for information as much as emotional support.

Other services, for example hospices, operate a system of follow up to the bereaved, allowing them to make use of it if they feel that they need help. This could still be seen as a form of reach-in service but as the hospice and hospice staff are often known to the relatives there may be more inclination for people to make use of the service.

'We have different ways of offering intervention or leaving it open for people to pick up on themselves. Very much it is left with the person to respond to the letter, to pick up at any time because I make it clear that it's not just for now, its for any time. I give them all the contact details and leave it with them' (Family Support Services Co-ordinator, hospice).

One example of reach-out from non-hospice based services was identified and this involved assessment forms being sent to the bereaved after a pre-determined length of time and a bereavement service being provided depending on results.

'At 6 & 12 months we send out a copy of the quality of life form, SF36, and the Hospital Anxiety and Depression (HADS) form along with a letter stating that we are well aware that this can be quite distressing and if they don't want to fill it out that's fine but it is a means of helping us find out if things are reasonable with them at that point of time' (Clinical Nurse Specialist 2).

Practitioners also believe that, to allow the acceptance of grief as a normal process, bereavement support should only be provided at a time when it is necessary and not to be perpetuated indefinitely.

'Time limited support so that dependency is not created' (Researcher 1).

3.5.4.1. Education for understanding grief and loss

Raising awareness of the normality and range of responses to loss is often a feature of educational programmes for professionals. Such programmes often encourage participants to draw on and recognise their own experience and response to grief, loss and bereavement. Interviewees in educational roles gave detailed descriptions of how the programmes they are involved with allow students to explore their own experiences of loss and bereavement. It is felt that this kind of preparatory work enables

people to be more responsive to the feelings of others and to acknowledge the range of normal responses to loss.

'Emphasis in teaching on grief as a normal process' (Education Programme Leader).

'Education for health and social care professionals should be developed within grief as a normal process but we need to be able to assess and identify those people who may need help' (Researcher 3).

'Theories can help us to understand why people cope the way they do. I link it with coping and communication skills, getting them to recognise what is normal for most people. The most important thing is to understand how people are feeling, that they need reassurance about how they feel, and getting people to recognise that they can be supportive' (Practice Educator 1).

Bereavement related issues are often considered along with the wider issues of loss, highlighted as especially relevant in some areas of health and social care, such as midwifery and Alzheimer's disease. Students are encouraged to consider the emotional consequences of loss whether or not it involves the death of another. Interviewees from a range of services gave examples of the consequence of loss, in its broader sense, for their clients. Particular examples occur around pregnancy and childbirth and in Alzheimer's disease where carers experience losses throughout the progress of the disease.

'Sometimes the concept of loss and bereavement is interpreted rather narrowly. People think about still birth, miscarriage, neonatal death but they may not be thinking about the infertile woman or the woman who places her baby for adoption, or the woman who hasn't had a very good experience, has had a highly medicalised birth when really she wanted an entirely physiological experience' (Researcher 4).

'The pregnancy and loss module is not solely about death but also deals with loss of sense of self through becoming pregnant, loss associated with not having a healthy baby, affect of pregnancy and childbirth on employment, preinatal loss, maternal loss. There has been a consistent interest in the topic' (Univeristy Lecturer 1).

'We also meet with people who are experiencing loss in a broader sense, for example relating to stroke, Parkinson's disease. We also see people in remission

> 'who are trying to adjust to possibly getting better and that can be a difficult area' (Bereavement Counsellor).

> 'I come in at the point of the cared for person moving into long term care. Death isn't the only loss, there are lots of wee deaths. Making the decision to go into care is worse than when the partner dies. They feel guilt from abandoning their partner, and relief as well. They feel guilty about feeling that relief' (Voluntary Worker).

In addition consideration of loss needs to extend to the loss of contact some carers have with health and social care professionals.

> 'Recognised sometimes when people with Alzheimer's or any kind of dementia move into long term care or die, the partner who has been caring on a 24hr/day basis for a number of years suddenly is abandoned with nobody. They have had carers, social workers, CPNs, GPs, people going in on a daily, twice, thrice daily basis depending on the needs....and then the next day there is nobody going in' (Voluntary Worker).

The normality of grief and loss may be less well understood by those who are not involved in bereavement work or have not undertaken an education programme in this area. There is some concern about the level of understanding of grief and loss in the wider population and the common belief that someone's experience is exceptional. This is attributed to broadly negative societal attitudes to death and dying. Many interviewees were advocates for inclusion of topics that would promote discussion of death, loss and grief in school curricula. Being more open about the topic from an early age may allow children to grow up with an understanding that grief is something that everyone will have to face during their lifetime. When there is a greater understanding people will be more prepared and have the skills to cope and be self caring when they become bereaved.

> 'Bereavement can be regarded as a normal part of growing up. It needs to be treated as a source of difference for some children but also as a mainstream issue. There is a strong argument for death education in schools and a need for policies about bereaved children' (Reader in Family Studies).

> 'Priorities are awareness raising and emotional education directed to everyone; in schools, home, etc' (Palliative Care Counsellor).

> 'Education would be one of the priorities, education of children. I think we give children lots of information about life but we hide away that death happens and people don't have the skills to deal with it' (Bereavement Co-ordinator 2, hospice).

There is some indication that some service providers already have close links with schools in their area and are addressing this directly.

> 'I do training for schools, helping schools develop bereavement care policies and action plans. Negotiating getting in on their teacher training and in-service days to put it on the map' (Voluntary Sector Practitioner, children and young people).

Although normalising grief, loss and bereavement is desirable there is also a need to consider bereavement in the broader public health or preventative medicine context. It may be possible to address this to some extent in the same, or similar, way as other health priorities have been addressed.

> 'The general population doesn't always understand what someone goes through. Bereavement awareness should be brought into health education along the lines of anti smoking messages etc' (Practice Educator 2).

> 'Bereavement as a public health issue. In a number of areas the public health co-ordinators have been developing bereavement care' (Cruse Bereavement Care Scotland).

> 'I do wish we looked at bereavement in relation to preventative medicine and mental health, its just so important. If we treated our bereaved better we wouldn't have half as many people going through mental health services' (Chief Executive, national voluntary organisation).

Bereavement may have a considerable impact on physical and mental health and also in social and economic terms. Practitioners are increasingly recognising the wider consequences of bereavement.

> 'There is a link between the broad issues of bereavement in young people (access, types of death i.e. peers, education, need for polices and dedicated personnel) with disadvantage and exclusion – social structural issues. There is a whole area of literature about social outcomes for bereaved young people; things like educational qualifications, teenage pregnancy' (Reader in Family Studies).

> 'We became very interested in what we saw as the long term damage that impacted on people's quality of life and possibly quality of health' (Specialist Health Policy Advisor).
>
> 'I suspect that deprivation would probably have an impact as well on the understanding of families, and the way people cope with bereavement' (GP 1).

Bereavement may also have a more general impact on the economy than has been recognised to date.

> 'Bereavement has a cost to the economy' (Researcher 2).
>
> 'Bereavement has a cost to the economy: days lost from work, bereaved school children, the prison population where bereavement is a huge issue and is often implicated in anti-social behaviour' (Cruse Bereavement Care Scotland).

In conclusion it appears that there needs to be wider recognition of grief as a normal process and active encouragement of use of self care strategies by the bereaved. The perceived need for the bereaved to access health and social care services may then be reduced. Education of practitioners in the field should enable them to open up discussion of these important issues that are strongly endorsed throughout the interviews. (Issues around education will be addressed more fully in Section 3.5.9.). There should also be wider recognition of the public health and economic issues, with further research to determine exactly what these are and to what extent they impact on individuals and society. This would help service providers to identify appropriate measures that could be taken to enable people to adapt appropriately to their losses.

3.5.5. Range and type of approaches to bereavement care

A considerable range of approaches to bereavement care already exist and practitioners are aware that no one approach suits all. Senior psychologists and researchers interviewed recommend that a choice of services should be available to the bereaved. The value of having a tiered approach that involves input from all levels of staff across the sectors has been highlighted. This should incorporate working from an evidence base with evaluation a key part of the service provided.

'What we have is a tiered model and the main part of this pyramid (base) is the majority of cases where ward staff support relatives. Then there is a smaller band towards the top of the pyramid where staff will contact us for information or support. There is another small band at the point of the pyramid which is where relatives contact us directly' (Bereavement Co-ordinator 1, hospital).

'A range of interventions are needed to address all aspects of bereavement care in different situations though efficacy still isn't established for many. Cruse can offer a range of input: skilled listening; advanced listening; counselling' (Researcher 2).

'Services should have adequate resources to have a menu of services' (Researcher 1).

'Trying to have a huge menu is what I would see as important so that people don't feel pathologised in any way' (Psychologist, hospice).

'It is increasingly being recognised that there needs to be a tiered approach to the delivery of specialist psychological care. I am a great believer in competency based approaches and not necessarily specifying professions. The majority of bereavement care doesn't require any particular skills from those working in psychological services but some of the core competencies of clinical psychologists in terms of evaluation, evidence base and setting up systems are underpinned by audit' (Consultant in Psycho-social Oncology).

From the descriptions of their services that people have given in the interviews it appears that there are a number of points at which the various services can be involved in a person's bereavement journey: before the death; at the time of the death; after the death (often at a much later stage), and where particular services may be involved. Table 5 below shows the perceived stages in this journey.

Some services provide bereavement care across all stages in the journey, whereas others are only providing care and support at a particular time. It may be the case, that the boundaries between the stages prevent any development of an integrated or co-ordinated service, particularly between the statutory health components and the voluntary sector. However, this may not represent all situations where local links may be functioning well, for example, between midwifery services and groups such as SANDS (Stillbirth And Neonatal Death Society) and BLISS (the

Table 5. Stage(s) of involvement in bereavement and bereavement care

Before	Immediate	Later
Hospice palliative care services		
Hospital cancer services		
Non cancer hospital services		
Primary care services		
		Non NHS cancer services (CLAN, Maggie's Centre)
Midwifery services		Links to voluntary organisations
	Faith group representatives	
	Emergency services including A&E	
	Funeral directors	
Nursing home staff		
		Local Authority services
		Bereavement and generic counsellors
		Voluntary and support organisations (eg Cruse, Alzheimers, Age Concern, helplines, Breathing Space etc)
		Mental Health services
		Occupational Health

Key:

■	Main stage(s) of involvement
■	Some involvement in some services
□	No involvement

premature baby charity). It also questions the extent to which voluntary agencies may wish to be involved or be able to engage with all the stages.

Hospice services describe providing pre-bereavement support which may include assessment of how the family will react to the death. They also support the family at the time of the death and continue that care for as long as required after the death. There are also services, such as that

provided to women and families after miscarriage, that provide care before and at the time of death but may link into external support networks that will take over at a later stage.

> 'We provide total care from the minute that the pregnancy has been diagnosed as non-viable or the baby having died in utero. Providing support through miscarriage, through labour and then providing support after. Then giving them information about how to contact support networks...there's quite a lot of people and organisations involved' (Sister, Early Pregnancy Assessment Unit).

For hospitals, in general (including cancer services), the service provided to the bereaved is less clear and the level of involvement may be determined by the length of time the dead person was in hospital. Providing pre-bereavement support for families will not be possible if the death is unexpected i.e. in an A&E department. The level of follow up of the bereaved from hospital staff is also an area that appears to be underdeveloped. However, some practitioners are beginning to consider the needs of bereaved families i.e. an intensive care unit follow up service at one large teaching hospital in Scotland. Evaluation of such services will be necessary to determine the value of these initiatives for use in other areas. It is also difficult to determine the extent to which primary care staff follow up the bereaved, even after they have cared for dying individuals in their own homes. Again this highlights a lack of information about the burden of bereavement care in the community.

There is clear faith based support (often chaplaincy) for the bereaved particularly at the time of death and immediately afterwards. However, the extent to which this is a continuation of pre bereavement care is largely unknown in an increasingly secular society. Obviously there are links to funeral directors who play an important role in the journey, although this is usually confined to the period immediately after death. The level of involvement of providers of faith based support with other service providers is unclear.

Voluntary services also become involved with the bereaved at different stages depending on the nature of the service. Some will carry out bereavement care as a continuation of their involvement with the family, for example Alzheimer's Scotland. Others like Cruse will only provide a

service at a much later stage in the bereavement journey. Some voluntary sector providers describe their role as supplementary to that of statutory providers. This type of provision adds to the variety and choice of support services made available to the bereaved.

As previously discussed, mental health services appear to have limited engagement with the issue of bereavement until people develop mental ill health, such as anxiety or depression. Although we were unable to gain an occupational health perspective directly it would also appear that some form of engagement or involvement only happens after the death.

3.5.5.1. Development of Bereavement Services in the UK

Bereavement services in the rest of the UK have developed in different ways; some in response to need within a community, others from the Bristol and Alder Hey enquiries, and many as a natural continuation of care for a person, their family and friends. As a particular focus for strategic developments in bereavement care in England, Wales and Northern Ireland, the enquiries have been a strong driving force behind much of the strategic developments in bereavement care including the development of bereavement coordinator posts. However, such posts have not been a feature of developments in Scotland.

'We have a helpline run by the Dept of Health. We took it over from the Retained Organs Commission when they finished' (Chief Executive, national voluntary organisation).

'The origin of the work goes back to the organ retention issues at Bristol and Alder Hey, because there was a recommendation in the CMO's report on that that said that all Trusts should provide bereavement care' (Policy Officer).

'We had the same issue here that I know you had in Scotland and of course became apparent in England and Wales about retained organs which really came out of the Alder Hey Report. It was thought that the best approach for Northern Ireland would be some kind of regional bereavement network that would include a number of area coordinators' (Deputy Director of Secondary Care).

> 'This model that we have developed here is based on a review of services primarily with NHS Trusts in England who we approached in April/May last year to find out from them because I think they are ahead of us on this. I think the guidance from the Chief Medical Officer and the Dept of Health and the impact that the Redfern and Kennedy inquiries had on really shaking things up south of the border has driven the development of services in bereavement care in the NHS in England in a way that it hasn't in Scotland as a result of devolution I'm sorry to say' (Bereavement Co-ordinator 1, hospital).

However, services have often developed based on local needs.

> 'The service used to be called (Region) Helpline. It started out as the (name) Outreach Helpline, in response to the (name) disaster' (Social Worker).
>
> 'The service was identified by a cross disciplinary group driven primarily by GPs. They identified this gap for young people, people whom it was not appropriate to refer on to adult psychiatric services' (Youth Counsellor).

3.5.5.2. Interventions

Within the various services that provide bereavement care at different stages in the trajectory of grief, there are a number of different ways in which care is provided. Obvious examples would be telephone helplines, one to one counselling and group therapies, although there is a rich diversity of other ways in which the needs of the bereaved are addressed. Often, within a service, a number of approaches are also available.

> 'I think the balance of 1-1 and group support actually helps' (Hospice Chaplain 2).
>
> 'We work in a variety of ways with families, sometimes one to one, I am often involved in running groups for bereaved parents and sometimes other family members as well, a bereavement newsletter, a telephone bereavement service' (Senior Social Worker, hospice).
>
> '...the support is very much informed with a conversational style...with a structured therapeutic approach. The main formal support would be one to one work for as long as the person needed. There's someone I've been seeing fortnightly now for the last 18 months' (Head of cancer support service).
>
> 'There are three areas on the continuum that we can provide a service to: those who require a normalisation of what they are going through (maybe a one off talk and providing some information); those who require to explore their grief

process; those who want to examine the implications of grief and their responses to it can be helped by being challenged or helped to dig deeper' (Cruse Bereavement Care Scotland).

'Between 30-40% of people that we see at any time are one session only people...our average number of sessions per client is 3.8. We run groups at certain times....sometimes you get clusters...sometimes you get a lot of dads facing being a single dad, so I will run a dads group' (Children and Family Support Worker).

A thread running through many of the interviews was that every bereaved person has individualised needs that demand an individualised approach to their care. Many described a period of assessment followed by the provision of a service tailored specifically to the needs of the person. Because needs change with time service providers also described being flexible to changing their interventions in response to the bereaved person.

'The service depends on the individual, we get them to talk to us and we offer information, advice and support. We try to tailor it specific to needs' (Chief Executive, national voluntary organisation).

'Different people have different needs arising out of bereavement at different times so there is no one solution' (Specialist Health Policy Advisor).

'Support should be flexible and respond to differing needs of families' (Bereavement Co-ordinator 3, hospice).

'Bereavement care is provided across a spectrum, recognising that everyone is different' (Cruse Bereavement Care Scotland).

'Trying to help them identify what their needs are seems essential to me and that's such a variable thing from one person to the other' (Ex-Hospice Consultant).

'Even within our own area we have an enormous spread of different types of need' (Children and Family Support Worker).

'For carers it is there as long as they need it and it is tailored to them as individuals' (Voluntary Worker).

This may be especially relevant in guiding children and adolescents through bereavement. Youth counsellors describe changes in need as

bereaved young people mature, encounter new challenges and develop new relationships.

'Really it is working out what the issues are and looking at those. It may be that it is about communication between the parents, maybe information that the children and young people don't have, information about cancer, about treatment, it depends just what it is' (Support Worker for Children and Young People, cancer support centre).

I think it so depends on the context of the person themselves and on the context of the bereavement. We tend to pick up people who are on the more vulnerable end of not coping with bereavement, outwith the normal grief reaction. Therefore, we have had referrals from young people who's parents have committed suicide, young people who have found their parents following an overdose, young people who's siblings have died, road traffic accidents. They say that everybody suffers but we all suffer differently so you can't make an assumption about other people' (Youth Counsellor).

'Research is needed to have that longevity, to see how someone copes, if they lose a parent at 10 how does their coping differ when they are 15 or 20' (Youth Counsellor).

Although it is recognised that people are all different and have individualised needs there may be a dichotomy in that a fair number are still supported or counselled in groups. It may be that it needs a professional to assist people to recognise that what they are experiencing is actually similar to what others also experience. When this is the case the best people to provide support may be those others who have similar experiences.

'The role of the group is to put bereavement into normality and normality is found as the group check it out with each other. Group members find value in hearing other people's stories but need direction from a trained leader' (Hospice Chaplain 1).

Some highly specialised or innovative 'newer' interventions are also being used in certain services especially counselling.

'The art therapy has been a development from the initial three years of the counselling service... young people were feeling excluded from engaging in the

talking therapy so we have developed it as another choice for them' (Youth Counsellor).

'For the art group...pupils who had lost a parent in the last 2-3years and also a smaller group who had lost a parent 5 plus years ago...the ones who have got past the worst of the chaos can be very supportive to the newly bereaved' (Children and Family Support Worker).

'My training has involved transactional analysis so I incorporate that into my involvement, particularly when they go through forms of guilt; what they should have done or ought to have done' (Bereavement Counsellor).

'The EMDR is a practical thing that can be done about trauma and people seem to like it. It works quicker than being referred to primary mental health teams or child and family psychiatry where its not currently used. I also do play therapy, narrative therapy, I use music, any kind of medium that helps to get the expression of grief out' (Voluntary Sector Practitioner, children and young people).

There may also be some individuals who need particular approaches for an appropriate period of time, such as those with more complex needs and staff providing care in certain situations.

'I think people with complicated needs are best seen in the community where there is continuity of care for a length of time' (Psychologist, hospice).

'We are involved in bereavement care through: helping residents through bereavement of family members while they are residents here; bereavement care of families of residents who die here or in hospital; grief of staff who have cared for a resident for perhaps many years; residents when a fellow resident dies; family of, especially spouse of a person suffering from Alzheimer's disease' (Nursing Home Manager).

3.5.5.3. Information

An important part of any service for the bereaved is to provide them with adequate information that reflects the choice of local and national services that are available. There is a perception that the availability, accessibility, production and content of information needs to be addressed so that the right type can be available to the bereaved at the right time.

> 'We believe that people need good information. Some people wouldn't want to use the service here, they may prefer to go to CRUSE or contact a national helpline and it is important they have that information' (Head of Education, Hospice).
>
> 'We really are keen to make sure that people have access to information and support and know where to go to access support. We have produced a handbook called 'After a Suicide', we hope this is a helpful resource and that is something that can be developed nationally' (Co-ordinator, government programme).
>
> 'There is a need for better information to be available for the bereaved: production and content' (Researcher 2).
>
> 'Giving them evidence based information and signposting them to the appropriate support instead of the experience people have of going round in circles trying to access the right help' (Consultant in Psycho-social Oncology).

Some practitioners described giving out standard pamphlets and booklets (provided by the NHS and local authorities) to the bereaved and some dissatisfaction for themselves at the content and format of such items.

> 'I do hand over to families information about what they need to do next but it is a very cold pamphlet...I feel that there could be something far better and more reassuring that could be handed to people' (Nursing Home Manager).
>
> 'We have leaflets about how to deal with death and what to do and I feel they are so horrendously impersonal' (GP 3).
>
> 'We have a new procedure where we can pronounce a life extinct. What we do is leave a form with the body for the police or undertaker and there is a letter/booklet for the relative. On the front of the envelope it says 'With Sympathy'. It's a horrible thing, I don't use it.....To me its not very professional I would rather speak to them about it and try and answer their questions' (Ambulance Paramedic).

Some co-ordination and shared awareness between the services of what information is provided by other practitioners in an area will be necessary before reliable local information can be produced.

> 'There are duplication of resources and information overload. The acute sector often doesn't know what is available in the community. No sharing between care homes, individual businesses. Important to highlight key booklets and also other local information' (Project Manager, non-malignant palliative care).

> 'We could do with publications that could collate the information needed and somehow make it a bit more uniform...a bit more presentable and thought through' (Patient and Family Support Person, hospice).

A natural place to look for information today is the internet and some practitioners see this as an important resource for the future and one that should be used, and indeed is being used, by service providers to reach the bereaved.

> 'Finding the right thing, the right types of information to pass on can be tricky. We probably see the future as being online' (Youth Counsellor).
>
> 'I think communicating existing resources so that people are aware of what already exists. So for the GPs I would always include the Cruse website, Cancer Bacup has something for children' (Psychologist, hospice).

3.5.5.4. Volunteers in bereavement care

Across the sectors a variety of people provide bereavement services, from clinical psychologists in some hospices to trained volunteers in voluntary organisations or within some hospices. Little evaluation has been carried out of bereavement care services but it appears that volunteers may be a valuable part of any tiered approach and may be well placed to provide a service within the context of grief as a normal part of life.

> 'Trained volunteers undertake the telephone befriending. The feedback from families is that it was nice to keep in touch with the hospice and that there was somebody who would talk to them, somebody who would listen. I do find that people respond well to telephone support if they know you' (Senior Social Worker, hospice).
>
> 'We set up one of the first palliative care bereavement services relying on volunteers because we always believed that grief is normal and that ordinary people can be hugely supportive of ordinary people living through extraordinary times in their lives. We found that the volunteers were able to provide a meaningful service. Despite all the methodological problems of trying to measure a service, we did find that volunteers could make a difference for services that have to justify their development. The volunteer support is very much about how to help people manage and understand and a lot of the time what they are doing is listening and giving information. Working with volunteers is like working with

'any group of people except that they don't get paid and they really do need to have a really strong sense of belonging to a service and of being valued and that their work is carefully set up' (Head of Education, Hospice).

Whilst volunteers may be valuable, their use necessitates a period of training, ongoing supervision and evaluation of the service with the concomitant time and resource implications.

'Volunteers provide invaluable support but this has implications for training, support and ongoing education' (Researcher 1).

'There are 500-600 volunteers in Scotland, all trained & supervised – 60 hour foundation course. Volunteers provide three intervention streams – skilled listener, advanced listener or counsellor' (Cruse Bereavement Care Scotland).

Following on from this concept of tiered care, where information and support needs can be provided appropriately by practitioners and agencies at each level, is the ability to refer on to the next level if necessary. In the voluntary sector an interviewee described referring people to other services if it was felt that their needs were not being met.

'If I was concerned that the service I was providing wasn't meeting the needs of the person then I would refer them on to a counsellor' (Voluntary Worker).

Having this kind of flexibility and communication with other services is important in addressing all the issues that the bereaved person may bring. Unfortunately, the same voluntary sector provider, describes a certain reluctance of practitioners to refer for reasons that are unclear. A greater understanding of each others' roles should be fostered in geographical areas that have this richness of provision to enable the bereaved to have the support they need. This may also be a symptom of the boundaries identified earlier in Table 5.

'I think sometimes, though we have a good working relationship with professionals, there are still barriers. Are we treading on toes? These professionals have huge case loads, that is the gap that my post fills. I am not taking over, it is a supplementary role and would relieve them of some of the care' (Voluntary Worker).

Importantly, we are reminded by a variety of interviewees throughout the study that bereavement is a normal process and that intervention is not required by the majority of the bereaved. Service providers describe a flexibility in which there is a need to promote self management and not to create dependency.

> 'The approach of self referral, non-intervention unless needed, are general principles that underlie any bereavement service. There needs to be recognition that most will accomplish their bereavement journey with community support' (Cruse Bereavement Care Scotland).)

A particular example of this ethos exists in the support of a family where a parent has died. Hospice staff working with a remaining parent see value in actively enabling him or her to support the children through their bereavement. The parent, having been given as much information as they need, should be allowed to make decisions within the family in the context of their usual coping mechanisms. Practitioners often try to maintain a balance between the amount of support they provide professionally and what the person/family get from each other or their community.

> 'Families should be encouraged to support one another and children should be helped in the context of the family' (Patient and Family Support Person, hospice).
>
> 'If you have to see a child you have to involve the whole family' (Patient and Family Support Person, hospice).
>
> 'The ideal people to support children are the parents but parents may need a lot of support to support the children' (Practice Educator 2).
>
> 'We try to support the parents in being the main holders of their children rather than working directly with the children. The ethos is preventative and trying to support the parents in the management of their own grief and their children's grief' (Children and Family Support Worker).
>
> 'Services should be sensitive to the need for not doing too much as it can be disempowering' (Patient and Family Support Person, hospice).
>
> 'It is important to get a balance though, by not taking over from their own support network and only being there when needed' (Clinical Nurse Specialist 1).

It is also important to be aware of the complex nature of relationships within some families when planning bereavement care services and helping them to help themselves. In some families, although all has been done to encourage self sufficiency, there may be some members not getting the support they need or want and professional intervention becomes necessary. Peer group support is seen as beneficial by some practitioners in maintaining bereavement support outside the services.

'Awareness of how good families can be in supporting each other if only they could a) realise that everyone grieves differently and b) that they could do so much in terms of supporting each other if there was greater open awareness about grief and the effect of grief on the different members of the family' (Researcher 3).

'Often in my situation it is the matriarch figure, granny, that held all the brothers and sisters, nieces and nephews and cousins together. There is a fear that the whole family system will collapse' (Nursing Home Manager).

 'I think often other patients and other relatives can be much more helpful in this respect (bereavement support) than professionals. I think patient to patient or client to client contact perhaps helps people to relate better to their own personal need' (Ex-Hospice Consultant).

'I think sometimes, just because you have a family structure doesn't mean that you will get the right care: I have to come here to cry so I don't upset the family or the family say I should be getting over it by now' (Specialist Health Policy Advisor).

3.5.5.5. Evidence based practice

Service providers are also seeking to base practice on available evidence of what works best, or they believe that research can help them to develop appropriate services. Evaluation of existing services may go some way in addressing this issue through examining what impact a service has on those who use it and how well it meets need within a local community.

'Service provision should have a strong evidence base' (Palliative Care Counsellor).

'I'm particularly interested in research. Particularly interested in how we can respond better to people who have been bereaved by suicide' (Co-ordinator, government programme).

'Research required into individuals' experiences: what helped/didn't help; anticipatory grief for patients and carers, and for children' (Researcher 3).

'Everyone is patting themselves on the back and saying "that is what we should be doing and this is what we are doing and isn't this great," when we've never actually evaluated it' (Head of Midwifery Education).

However, a small number of interviewees voiced concern about the value of carrying out more research into bereavement.

'Centre for bereavement care not workable, there is enough research' (Chaplain, hospice 1).

'There is already a lot of research out there and there are no new messages to be identified' (Palliative Care Research Nurse).

Some thought that having a Bereavement Centre where research activity could be based, a key message from Phase 1 of this work, would be useful though localised research activities should not be phased out.

'Research posts, that would be helpful, we find it very difficult as practitioners to do research as well....I would be very keen to have a Centre for Bereavement Care in Scotland' (Children and Family Support Worker).

'On a bereavement centre, it would need a lot of resources, but it would be good to do that. I wonder if it should be a separate centre or should work with the organisations that are trying to do things with bereavement support already e.g. CRUSE. It could be a collaborative thing. I wouldn't like to see the pockets of very good practice not being utilised and a centre doing everything' (Practice Educator 1).

Bereavement services in some specialist areas, particularly hospice and palliative care, appear to be well developed. Other services are currently developing their capacity in caring for the relatives and friends of someone who has died in their care. This expansion of provision and increase in options for the bereaved should be encouraged using the skills and experience of all levels of staff to their maximum. Co-ordination of services and information with awareness between practitioners of each

other's roles is essential to providing a holistic service to the bereaved should the need arise. Although not fully supported, research and development activity and evaluation of services could be central to providing high quality care and support which promotes and nurtures self management in the bereaved.

3.5.6. Co-ordination and Communication

There is a variety of approaches, at both local and national levels, to providing services and support for the bereaved as discussed in section 3.5.5. However, what is viewed as missing is some form of co-ordination, networking or linkage between the different facets.

'There is no co-ordinated approach to bereavement nationally' (Practice Educator 2).

'There is a need for co-ordination of activity around bereavement care: the range and type of information; the range and type of access' (Researcher 2).

'There are odd pockets but there is no co-ordination' (Cruse Bereavement Care Scotland).

'There is poor co-ordination between service providers...more collaboration between agencies is needed' (Funeral Director).

'A co-ordinated approach to bereavement and bereavement care across statutory and voluntary agencies is definitely needed; different groups doing things but no-one knows exactly what is on offer' (Support Worker for Children and Young People, cancer support centre).

It appears that service providers are often unaware of what else exists for the bereaved in their local area or on a national basis. Some saw co-ordination as providing a means by which not only care and support of the bereaved could be enhanced but could also be beneficial to the practitioner.

'A better co-ordination of services would be very helpful, not only for the bereaved but for people like myself who are trying to help the bereaved' (Social Worker).

'Perhaps somehow co-ordinating the whole family care, knowing the whole situation and having someone to go in there and recognise the need I feel would

> be better for them (the bereaved). Just having someone who has that interest, has the time and the dedicated staff to do it' (Ex-Hospice Consultant).

Enabling people to work together may have a cumulative effect on practice and practitioners that could not be achieved by individuals working alone in their own environments.

> '...if you set up mechanisms in a locality that synthesises people's efforts and share information and are not precious about all the boundaries and you encourage people to muck in and share then in the longer term you get a much bigger impact than you would if you just focus in on particular areas or keep people separate' (Chairperson, bereavement working group).
>
> 'Continuity of information, education and support over each area is needed. I would like to see hospitals having a person there for supporting bereaved people. It would have to be somebody who is employed for that reason' (Practice Educator 1).
>
> Part of our development is about linking networks together not always about creating services but creating referral pathways and making sure that people are aware of things' (Co-ordinator, government programme).
>
> 'I don't have any problem joining in with other statutory services. We have single shared assessment' (Voluntary Worker).

It was clear throughout the interviews that there are some existing informal networks and attempts at co-ordination, across health and social care and the voluntary sector. The extent to which such initiatives are successful or have been evaluated seems variable. However, there is also isolation of practitioners and agencies and, on the whole, limited interagency working.

> 'There are a lot of informal links with services in the surrounding area i.e. lunch clubs' (Chaplain, hospice 1).
>
> 'I tried to get GPs to interconnect in that if they felt that they had a patient who had died and significant others were not registered at the practice to actually alert the GPs of these patients...so that these people could be watched out for but it never really, I never got the coordination of that quite right' (GP 3).
>
> 'I get the impression that people are still working in isolation and perhaps without as much executive support as you might expect' (Policy Officer).

'I try to look to grow a collaborative model. In reality, to get a full service with other bereavement workers is challenging. We can either work jointly or at a connected distance' (Voluntary Sector Practitioner, children and young people).

A gap between where medical care finishes and social care begins has been described and some co-ordination between the services may help to smooth the transition between the two for the bereaved.

'There is a grey area where medical care finishes and social care begins. That gap needs to be ironed out and services brought together' (Social Care Team Leader).

One hospice based practitioner described her service as a resource for the community. If this is to be workable then some co-ordination and awareness of what is available in that community would be required to prevent too great a demand being put on the service.

'What I would tell our staff is that we are a resource for the community. That means we don't have to do it all ourselves' (Psychologist, hospice).

GPs may be in the best position to co-ordinate bereavement services in the community. However, again individual services would probably be unable to cope with demand if it was better known or offered more widely.

'General Practice, at the moment is ideally suited to tie in all these things and I don't think we need to put in another layer of something because it gets complicated' (GP 3).

Development of bereavement co-ordinator posts within health authorities in other parts of the UK has already taken place in response to the organ retention reports (see section 3.5.5.1.). Staff have only recently been appointed to these posts and they have not yet been subject to evaluation.

'We set up a steering group in the department to look at co-ordination of services. The more that was discussed the more it was thought that the best approach for (country) would be some kind of regional bereavement network that would include a number of area co-ordinators. The co-ordinators are not themselves bereavement counsellors. It is their job to provide a service and co-ordinate training and ensure certain standards are met and so forth' (Deputy Director of Secondary Care).

> 'Bereavement link nurses in each area can be a useful addition to the process for cascade of information and also in a hands on capacity to support others' (Bereavement Care Manager, hospital).

The development of these roles in practice will be interesting to watch and their evaluation critical to inform the future direction of bereavement care. To our knowledge only one co-ordinator post has been developed in Scotland to date, within a university hospital and funded for two years from April 2005. The post holder is responsible for: developing a strategy in relation to bereavement; training; looking at facilities for supporting bereaved families; piloting of a service to support relatives and staff when someone dies in hospital.

> 'There wasn't a single co-ordinating point of communication between i.e. the ward staff and the porters, or the porters and the staff in the mortuary, or the relatives and the mortuary staff and the funeral directors and the procurator fiscal and on and on it went. It was decided to create a post for someone to co-ordinate those issues. It has been set up initially as a two year endowment funded project so what I have responsibility for doing is tackling some of the issues that have arisen and then also developing a project outlining what sort of permanent bereavement centre we need within our hospitals division' (Bereavement Co-ordinator 1, hospital).

Some sharing of ideas has been ongoing between services in Scotland thus enabling providers in different areas to use existing frameworks and ideas when developing their services. Collaboration and sharing of ideas between practitioners is vital for the development of high quality bereavement care services in Scotland.

> '(Other area) got in touch with us before they set up their service and used a similar model...adapted to their own particular area' (Children and Family Support Worker).
>
> 'The only thing is this issue of networking. I see it as a key, sharing practice and not reinventing the wheel...Quite often we hear....that its been so helpful to meet staff working in bereavement care elsewhere. We've acted as a catalyst' (Policy Advisor).

In developing co-ordination type services it may be worth examining a networking initiative set up within a research establishment elsewhere.

This type of group may be one way of bringing services together to examine and share best practice and could be a function of a Centre for Bereavement Care.

> 'There was a sense that the bereavement field and services were fragmented and poorly linked to mainstream health services. Our first two tasks were to undertake a scoping study of bereavement services and programs throughout the State and to publish a directory for general practitioners and other health services. Other bereavement organisations are members of the Centre and have close working relationships with us. We operate a Bereavement Network, which is comprised of about 20 agencies (some bereavement specific, others more generalist), and this group meets quarterly. We also place clinical interns in a number of these agencies so there is a direct service component to our relationship.   We conduct bi-monthly journal clubs throughout the State and these have the advantage of strengthening the networks between organisations as well as exposing participants to evidence based literature.   We have deliberately drawn widely in terms of the governance of the organisation and the content of programs and have people with diverse backgrounds in medicine, nursing, palliative care, clergy, sociology, journalism, business, social work, psychology and medical education' (Director, Centre for Grief and Bereavement).

An example of some aspects of this type of work being carried out in Scotland has been within a regional NHS Palliative Care Service, though there may be others.

> 'I set up a thing called (region) Children Loss and Bereavement Forum, which is professionals who are involved with bereaved children cross sector and we provide training through that and try and look at issues of policy and so on....I'm sure (region) isn't unique in this' (Children and Family Support Worker).

Practitioners believe that such inter-disciplinary collaboration and communication would enhance the care of the bereaved by enabling information sharing and improved access to services. Central to this is improvement in communication between the services and with the bereaved. Some interviewees have described communication between service providers as lacking while one interviewee who has been carrying out a bereavement follow up service has noticed improvement in communication between professionals and with the bereaved since the inception of her service.

'There needs to be more dialogue and inter-disciplinary working' (Reader in Family Studies).

'Collaboration with teams, including the district nursing team is important' (Palliative Care Counsellor).

'Having a good relationship with the community nursing staff is central to this working well' (GP 3).

'The impact, from what relatives have said, is that it (follow up service) has assisted us to try harder in our communication. Communication has been the biggest aspect I think. It is important that people do have a means of communication and that they are able to identify someone who they can go to, who they feel they can trust and will understand what issues they may have. It's very easy for people to just slip through a net and to feel quite abandoned so its trying to prevent that. It is so varied out in the community' (Clinical Nurse Specialist 2).

The key challenge for service providers in Scotland is to be able to develop effective co-ordination, networking and linkage between the services in their area and with providers in other areas. Evidence from elsewhere suggests that some form of overall co-ordination, via a centre, can be helpful. Evaluation of bereavement co-ordinator posts in health services across the UK will be required to determine their benefit to the bereaved and to other service providers and will be crucial to inform the development of new co-ordination roles. Finally, communication and collaboration appear essential to providing an holistic service to the bereaved that is evidence based and accessible.

3.5.7. Follow up for the bereaved

Follow up for the bereaved may be initiated in different ways and varies from the formal in some hospice based services to informal by some primary care and social care practitioners.

'We send out about 60 letters a month to the principal member of the family inviting them to our bereavement support service. The bereavement support service is structured around small group work. The idea is that we leave people alone for between 8-12 weeks. We may be in touch before if there are any risk factors. We also offer a one to one service if they wish. We make up small groups of people with something in common; sibling loss, partner loss, loss of a

child. It is very very rare in the group work that we identify someone who needs further input from a CPN or bereavement counselling or whatever' (Hospice Chaplain 1).

'If they are following them up (community nurse) and seeing them on a regular basis as well there is probably not much point in us both going in too frequently, as long as somebody's going in it doesn't really matter (who it is)' (GP 2).

'In the community the DNs did feel that they carried out a bereavement visit when they went back to the home to collect equipment but didn't visit again unless they were asked to. They often see people in the street. Staff didn't see bereavement care as an issue' (Palliative Care Research Nurse).

'I sometimes go back to the relative a few weeks later if I have been involved with the family. I just sit and chat about the person. The relatives like me to do that' (Social Care Team Leader).

Most hospice based follow up services are well structured and make contact with bereaved relatives at definite intervals e.g. six weeks, four months, a year. Sending out sympathy cards or anniversary cards containing contact details of the bereavement service providers are common ways of saying that the hospice staff haven't forgotten the bereaved person and of reminding them about the service available. However, other examples of formal follow up are also found in hospitals, primary care and in the independent sector.

'We have a full service of a year post bereavement following a stay in intensive care. Within that at six weeks we send out a card, just a very plain card to say 'we are here if there is anything that you need' and gives a contact name and number. At six months we send out a copy of the quality of life form, SF36, and the Hospital Anxiety and Depressions form (HADS) along with a letter stating that we are well aware that this can be quite distressing and if they don't want to fill it out that's fine but it is a means of helping us find out if things are reasonable with them at that point of time. Then at a year, if the forms were sent back at six months I would send a second set out, just to make sure that things are going the right way but everyone who has been through intensive care and suffered a bereavement receives an anniversary card, again just saying that the organisation does remember them and if there is anything that we can do there is a contact name and number again' (Clinical Nurse Specialist 2).

'Being a GP in family care I am involved with individual patients but also the family and extended family. I follow people up over several years. The district nurse or myself do a follow up visit usually to the house. You take a little time to gauge how the relative is coping, coming to terms with the situation. We formally do that. When would depend on how much contact we've had and how we expect things to go. Not immediately after the funeral, we leave it maybe a week or longer. Sometimes we decide we need more follow up and we ask the person to come along to meet and go over certain aspects. A lot of what we do is communicating and trying to gauge what people's understanding is and to clarify and raise things and put it in perspective' (GP 1).

'Our district nurse who has usually been involved with these patients ...does bereavement visiting...she can alert us to any issues' (GP 3).

'I do a lot of follow up. Relatives become friends, they are not just visitors to the nursing home...I always phone them, visit them after the death. I help them through their initial bereavement and grief. I also often involve the care manager of the person that has died' (Nursing Home Manager).

Hospices in Scotland often employ a faith group representative, generally a Church of Scotland Chaplain. Where this is the case running a memorial service is a common means of following up bereaved relatives and friends. These events provide an appropriate opportunity for the bereaved to talk with staff and to raise any difficulties that they may have been experiencing. Staff also have an opportunity to remind people of the services that they provide.

'We also have a memorial event – invite everyone to that. We used to hold it twice a year – people get quite upset and the staff recognise this and are comfortable with people being upset and recognise that's quite normal' (Chaplain, hospice 2).

'There is a memorial service (at hospice) at least once a year. It does help people reflect and move on. It helps people to see grief as a normal process and that other people have been affected. It takes the isolation away from grief' (Researcher 3).

'The time of remembrance is a mix of music and readings, there is ritual in it, people light a small candle, they are given a small card to write something personal and that can go in a book, there are flowers that people can take away if

they want. Its about having a ritual that is meaningful and inclusive for everyone' (Psychologist, hospice).

'We had our first remembrance service last year and the response was overwhelming. Something about how do we create a very sacred and special place for people to come and acknowledge, that acknowledgement of this grief' (Bereavement Co-ordinator 2, hospice).

Although bereavement follow up, in some areas, appears to be comprehensive, there are areas where service provision is sporadic, even within cancer and palliative care services.

'I have concerns in areas such as cancer because there is so much support for people when they are dying and once they are dead all these organisations drop them. Not only are they suffering the loss they are suffering rejection from the organisation as well' (Chief Executive, national voluntary organisation).

'There are concerns about those who don't use bereavement services: we wonder if there should be a safety net later in the year, sending out an anniversary card so that those may be picked up' (Hospice Chaplain 1).

'People aren't supported enough and I want to set up proper follow up for all families (of young people with cancer aged 13-23 years) for up to 2 years. People should get the chance to voice what they want and if they want to meet up with other families who have gone through similar then it can be facilitated' (Clinical Nurse Specialist 1).

'I lost my wife 6 months ago. The bereavement care I have had from the hospice has been absolutely nil and that has been a bit of a disappointment. My son and my daughter and myself have received no follow up whatsoever' (Ex-hospice Consultant).

There is also a suggestion, in this study, that the bereaved prefer support to be available locally, although this may be unavailable in some areas particularly for specific needs. However, there may be situations where people will more readily access a national service through, for example, a helpline or website. What appears to be important is that a choice of approaches is maintained to provide for the needs of each bereaved person.

'People like a local person to speak to' (Funeral Director).

'What I would like to see is a support group for girls that miscarry. There isn't a support network in (city) and there is a need' (Sister, Early Pregnancy Assessment Unit).

'I think also that there is less stigma in cities than in isolated places. We are keen to support national help lines, Breathing Space, Childline and Samaritans – they are an anonymous accessible facility. Maybe things like bereavement hotlines ensure that national services can be accessed for people remotely. Again self help and other resources on the website' (Co-ordinator, government programme)

Despite the growing secularisation of our society, there is no doubt that established figures in the community can still play an important role in supporting the bereaved.

'Parish Ministry plays a crucial role in bereavement support for the community as a whole. This begins with the initial visit to plan the funeral' (Parish Minister).

Some service providers prefer that people recognise their own needs for additional help and support or have an opportunity to discuss the death and to access the appropriate services without professional direction (reach in). See also Section 3.5.4.

'We operate as an in-reach service, based on research which shows better outcomes when the client reaches into services' (Cruse Bereavement Care Scotland).

Others will go part of the way, particularly hospice services, by providing details of the bereavement care they offer and providing reminders of their contact details to the bereaved at appropriate intervals (reach out). The 'reach in' perspective is often the main approach of many voluntary agencies, such as Cruse. However, the partial 'reach out' process appears to be well received by the bereaved and does not result in an overwhelming 'reach back in' response. Some practitioners describe a desire to help people to manage rather than waiting for them to get into difficulties.

'Are we talking about helping communities to be better at supporting bereaved people and being more aware so that people get the support or are we saying that we need to help those that have serious problems? My heart is in helping

people manage rather than about waiting for them to get into difficulty. We are reaching out to people that the nurses have identified that the death was particularly harrowing, the illness was particularly harrowing, they are isolated and that there is more conflict in the family, multiple losses that we know are going to stress their coping resources' (Head of Education, Hospice).

Many practitioners also recognise the value of pre-bereavement engagement in that it can reduce the need for additional follow up and support after the death. That is, bereavement support does not suddenly start at death but is part of on-going care that begins at some indeterminate time before death.

'Bereavement should be seen as a continuum' (Palliative Care Counsellor).

Again this type of preparatory work and anticipatory assessment is commonly, but not exclusively, carried out in hospices where close relationships can and do build up between staff and a patient's family.

'Sometimes if we do a bit of work before the death that is sufficient and people don't need follow through, other times they need a lot. If you help parents to prepare for some of the difficulties they may face they are less wrong footed by them' (Children and Family Support Worker).

'Bereavement care should start before the death as part of the palliative care process' (Specialist Health Policy Advisor).

'Pre-death support has always been available. We would see that as part of bereavement support. Preparing people beforehand, some want to discuss it more than others' (Psychologist, hospice).

'I have quite a broad look of bereavement and I believe if you can do good anticipatory grief before somebody dies then that helps them cope with grief as a normal process' (Researcher 3).

'Bereavement starts even before they pass away and once they have passed away I find that the more time I have spent with the relatives beforehand, the easier it is, a lot of the ground has been gone over already' (GP 1).

'Because they (staff) usually know family members already as they have seen them before the person has died, they are in a good position to offer bereavement support' (Head of cancer support service).

However, undertaking significant pre bereavement care is not always possible and for some health care workers in particular there is no opportunity to develop a relationship pre death with the bereaved, for example, ambulance paramedics attending a sudden death.

> 'The wife is in the car and you have to tell them (husband is dead) ....we're breaking bad news more often than good news' (Ambulance Paramedic).

This being the case there is still potential for risk assessment of the bereaved to be undertaken and, where necessary, flagged up to appropriate professionals for follow up. Risk assessment in general is varied in approach, from formal assessment tools to more informal case discussion approaches. Both approaches seem to be useful in identifying those who may be most at risk of a complicated grief response and in need of additional support of some form, but caution is urged to understand that individuals will react and cope differently, often in unexpected ways.

> 'The bereavement risk assessment form that we use is based on the one that Colin Murray Parkes used about 20 years ago. We have simplified it as much as possible so the staff can comment themselves on significant issues. We would see it as a guideline' (Psychologist, hospice).
>
> 'Assessment tool – I pinched it from 'A Gift of Tears'. It's a text book. It's a very simple tool, with 3 columns and different statements and whichever statements you circle – the more they are to the right the greater the risk of complications' (Bereavement Counsellor).
>
> 'We don't use a formal risk assessment tool but we do it within the context of the team' (Hospice Chaplain 1).
>
> 'My district nurse and myself and administrator have bereavement meetings where we will go through historical record sheets of patients...once every three months...we will consult the computer to see if that patient has been in to the surgery. It would be put in the clinical notes and that can just change the tack of the way you deal with them' (GP 3).

Opinions of interviewees were varied regarding the value of carrying out risk assessment of the bereaved. Some raised concerns about making attempts to pigeon-hole individuals whose needs were often diverse and differed at different times.

> 'I have a bit of difficulty with this risk factors business. I think it is so individual that how they feel they are coping has to be uniquely about their perspective and where they are coming from' (Children and Family Support Worker).

Others were more ambivalent but felt that formal risk assessment as a one off event at the time of death was of little value.

> 'You can argue both ways on the validity of doing risk assessment, you can argue that they are helpful or unhelpful and the research is ambivalent in that whole area. What doesn't work and we used to do this here was a risk assessment done by the nurse on duty at the time of the death. All that gives you is a photograph of that moment of loss, it gives you little or nothing about the running video tape of what people are living with, and it is very subjective. What one person may see as an over reaction, another may see as perfectly normal within the bounds of the relationship between that son and that mother' (Chaplain, hospice 1).

However, there was general support for some form of risk assessment, even if it wasn't formalised, that could also be used to bring potential difficulties to the attention of colleagues or other service providers.

> 'We are reaching out to people that the nurses have identified that the death was particularly harrowing, the illness was particularly harrowing, they are isolated and that there is more conflict in the family, multiple losses that we know are going to stress their coping resources' (Head of Education, hospice).
>
> 'I've also got a spectrum that I use in terms of trauma, so for example, did the child witness the death (etc) ...it gives us an idea of what traumatic events there were to the bereavement. I'm looking for the trauma as an initial starting point...we are trying to locate where the individual is in the process of mourning' (Voluntary sector practitioner, children and young people).
>
> 'Initially I would be assessing for a few weeks and if I felt they needed counselling I would suggest that. I find that if we are working with people before the death it can be very helpful' (Patient and Family Support Person, hospice).
>
> 'I'm very into risk factors. If we are aware of previous bereavements, low income, a lot of children under 12, the risk factors that Colin Murray Parkes talks about, I think we could highlight who might have an abnormal response' (Researcher 3).

Risk assessment can have different meanings to different practitioners and no one standard approach appears to exist. Whilst there is some disagreement about use, one practitioner warns that there is no point in performing a risk assessment if there is no provision of a service aimed at addressing the range of difficulties likely to be revealed.

'Don't risk assess unless you can do something about it' (Chaplain, hospice 2).

The interviewees in the study have been largely in favour of following up bereaved relatives, though engagement of staff is variable. Hospice services are particularly well structured to provide bereavement follow up and many provide a comprehensive service within their scope. In reality, the nature of death and the range of bereavement experiences are diverse and on the whole no service exists that provides assessment and follow up for the majority of bereaved people. The hospice model may form a useful template for service development in other areas. There is sporadic provision within other services, but localised assessment of need and development of a practical solution to bereavement follow up is necessary. More widespread pre-bereavement work where possible, including assessment and identification of risk factors, may be the most that some services can offer, but would still be seen as a useful contribution. Evaluation of existing services that includes the views of the bereaved would be invaluable in informing the development of new follow up services.

3.5.8. Guidance

Whilst there may be guidance, standards or policies for professionals for what to do around death and dying it is perceived that there is little or no accompanying work for bereavement care.

'NHS (region) has a policy for caring for the patient after death but there is no policy for bereavement care' (Chaplain, NHS).

'We have national frameworks for pretty much everything in Scotland...bereavement seems to have kind of slipped through all of these and yet it is such a global phenomenon' (Chairperson, bereavement working group).

However, some interviewees did mention specific guidance, standards and policies that incorporated caring for the bereaved.

> 'All through clinical governance there are issues of dignity and family support at the time of death' (Clinical Governance Co-ordinator).
>
> 'If you take things like standards for better health and NICE guidelines and the NSFs collectively it becomes apparent that they do all mention bereavement in its own right. At least a platform on which to build it is being acknowledged and it makes it easier at a local level to ask if we can get this on the agenda from a variety of different angles' (Bereavement Services Manager, hospital).
>
> 'We produced a document here, which was really a code of good practice around post-mortem examination' (Deputy Director of Secondary Care).
>
> 'We have policies for care of the dying that involves what we do for their relatives but made in a very broad sense so that we can identify different needs of different individuals. We have policies in place for expected and unexpected death' (Nursing Home Manager).

Having standards, guidance or policies is considered useful as they provide a starting point from which services could develop, particularly for those with less experience of dealing with the bereaved. Some stressed a need to take a national approach to setting standards for bereavement care in Scotland.

> 'We have standards and procedures for those less experienced and unfamiliar. Protocols are a good guide for them. It is in the nature of a good carer to be compassionate and sensitive, but with no standard procedures it can make them more anxious than need be' (University Lecturer 1).
>
> 'There is a need for the development of policies and guidelines because there are differences between areas' (Practice Educator 2).
>
> 'There has to be standards in bereavement care' (Chairperson, bereavement working group).
>
> 'We need to have standardised policies (region) wide or even Scottish wide' (Clinical Governance Co-ordinator).
>
> 'If there is no specific target or standard, then bereavement care gets left behind' (Policy Advisor).

As guidelines, standards and policies can reduce the variability in practice and foster common approaches to tackling the difficulties faced by some bereaved people, they may be a useful foundation for local practice development. However, there are also some notes of caution in that such tools should reflect local practices and more importantly should actually address the individualised needs of the bereaved.

'It seems to me that to have standards and guidance is helpful, at the local level at least you can have a common point at which you are aiming. 'When a patient dies' in England will prove to be an immensely valuable platform on which to build. If you have a standard or guidance it can provide a minimum level that can be adapted to the local community' (Bereavement Services Manager, hospital).

'I think it is about teaching people that guidelines are really a framework and you hang things on them and I think that trying to understand individuality is good' (Head of Midwifery Education).

'I would argue that there needs to be an informal element as well as a formal one' (Chairperson, bereavement working group).

Many interviewees agreed that there needed to be some development and availability of guidelines or standards of care in bereavement care services. However, there was some scepticism about whether some guidelines or standards would have an impact on the care given to the bereaved.

'We comply with the guidelines and we can tick all the boxes but there is very little evaluation of whether or not that meets the parents needs' (Head of Midwifery Education).

'Standards etc....need to be considered with a soft touch, not too much like the "ticky" boxes that come out of hospitals and you know we don't look at them half the time' (GP 3).

In addition broader issues were raised about developing such approaches as they may be interpreted in different ways or be lost in a plethora of other central advice.

'Standards, policies and guidelines, some of it is unhelpful. It can be helpful if it makes you look at practice. It is policing and not trusting that people really want to try and do their best' (Children and Family Support Worker).

'The Executive is awash with strategies but I do think it would be good if there were a list of priorities in order to guide developments locally and nationally' (Co-ordinator, government programme).

However, some form of framework appears to be considered a positive thing to develop practice in bereavement care.

'What we kind of need in Scotland is...a national framework' (Chairperson, bereavement working group).

However, creating such a framework may involve financial commitment. Achieving even the present levels of care and support can be demanding on resources in both statutory and voluntary sectors. There appears to be little allocated funding currently and service providers often juggle attempts to provide high quality bereavement care along with other commitments.

'I think that in the last national study the main reason why services (bereavement) are struggling is that we are at the Cinderella end and that is in quite a well resourced area of health care' (Hospice care) (Head of Education, hospice).

'It's always helpful to be backed up by cash to kick things off. It would be good to have something that comes from a higher level that actually permits local authorities and voluntary agencies to consider bereavement as a health service' (Co-ordinator, government programme).

'Here in (region) I can't get funding from health. I'm funded through Choose Life which is Scottish Exec money for (city) but I can't go out to (surrounding areas) because health haven't contributed to the pot' (Voluntary sector practitioner, children and young people).

'There is a lack of core funding, otherwise we could do better quality assurance with more central staff' (Cruse Bereavement Care Scotland).

'I think there should be core funding for a baseline service so that people wherever they live, can get the same kind of response. The reality is that people still find themselves with nothing' (Youth Counsellor).

Despite such financial limitations, developing bereavement care is not just about money but also about understanding the need and the degree of priority or importance that bereavement care is given within health and social care.

> 'In our financial climate it is extremely difficult to see how it could be done because unless people are willing to take on some of that within their own time a lot of it will not happen. I think it needs to be seen as an area away from anything else and it is not caught up in the financial aspects of the wider NHS' (Clinical Nurse Specialist 2).
>
> 'There is going to be a set of standard statements produced including bereavement care (for nursing homes in city Health Board area), but there is no staff support to put it into practice' (Project Manager, non-malignant palliative care).
>
> 'There needs to be an investment of attention and understanding as well as money' (Cruse Bereavement Care Scotland).

Development of a framework for bereavement care could proceed using current evidence, with evaluation and updating undertaken as necessary. The identification of a centre or group to take forward this work has been suggested.

> '.....within the literature review there was a proposal for a centre, a kind of centre of excellence...around bereavement and it would seem to fit. I think someone in the Executive needs to take responsibility to take this forward in partnership with key national agencies like Cruse etc' (Chairperson, bereavement working group).

In common with the other themes extracted from the interview data, networking and sharing of information is thought to be critical for the development of high quality services in Scotland. This can occur at a local level, between neighbouring areas or nationally. The impact of this kind of partnership working is much greater than that of isolated practitioners developing services from scratch, which often occurs. There needs to be a co-ordinated approach to the development of a framework for bereavement care that could include guidance, standards and policies. High quality bereavement care then has a chance of being available and accessible to all who may have a requirement at any stage in their bereavement journey.

3.5.9. Professional educational needs

> 'There is a need to get support at death right first time as there is no opportunity to recover the ground' (University Lecturer 2).

Professional education was identified as a crucial factor in the development and provision of high quality bereavement care across all sectors and for all levels of involvement. Many interviewees, across a range of professional groups indicated that education on bereavement was very important. It appears practitioners, and others, consider that improved provision of courses, modules, seminars and workshops on bereavement care could enhance understanding of the process of bereavement, its consequences and the factors that can contribute to practitioners being able to 'get it right first time'.

> 'There needs to be more education to understand about bereavement and what bereavement care really consists of. Education within the community as well because a lot of families can be torn apart by a bereavement and it is appreciating that people are very different' (Clinical Nurse Specialist 2).
>
> 'Education and professional development is a priority, because the bereavement care service is dependent on the staff within it. If Trusts don't invest time to train and develop staff....' (Policy Officer).
>
> 'There is no in-service training for social care officers to guide them and some of them find palliative care quite stressful and even more so if they find someone dead. We need a lot more training to provide bereavement care to families. I would just love to know the right words to use' (Social Care Team Leader).
>
> 'In education it is a priority for all organisations to offer training on normal grief and how to support someone who has been bereaved. Bereavement awareness should be brought into health education' (Practice Educator 2).
>
> 'Education for professionals on what is normal and abnormal is very important and particularly true for doctors' (Chaplain, hospice 1).
>
> 'There needs to be a lot more training on attitudes and developing positive attitudes to bereavement care' (Nursing Home Manager).
>
> 'More training for staff is an area I would like to see more work in...it is part of the role of the midwife: pregnancy loss' (Sister, Early Pregnancy Assessment Unit).

> 'We just don't get enough training on breaking bad news....we don't get any training on what to say and how to say it and it reflects on our practice' (Ambulance Paramedic).

Additionally, professional development may be about available and accessible information as much as it is about specific programmes of education.

> 'There is a gap in the access to information and resources that enable NHS staff to feel knowledgeable and competent in what they are doing' (Consultant of Psychosocial Oncology).

Furthermore, there are questions about who should actually undertake provision of bereavement care education.

> 'In the (national) context I think there are possibly gaps in the training and there is an issue around whose responsibility is it to do this' (Deputy Director of Secondary Care).

Despite such questions, a variety of education provision is perceived as important which should have cover all staff, including areas of practice which may not initially be considered.

> 'We need to build up the skills in the staff....There is a huge gap in health services in supporting our staff through death....I would like to see it become part of induction, training days, the training directory' (Clinical Governance Co-ordinator).
>
> 'It is in need of development, but there is quite a lot being done and it is always well received which would suggest that the need is there. I would like to see my own interests like learning disabilities being more widely taught. I think this is a neglected group where there may be chronic mental health problems and people with dementia' (Psychologist, hospice).

The outcome could be that staff engage more fully with the bereaved instead of being unsure of what to do and how to approach them.

> 'It is a priority to be providing some training and education for the staff so that all staff are more confident....that they don't hang back when they should be supporting' (Patient and Family Support Person, hospice)

This should also be taken to include undergraduate curricula, particularly for nursing and medical students.

> 'I think there is very little even in nurses' or medical students' training about bereavement...and all of a sudden they find themselves on a ward and they feel unequipped, they are young, they may never have personally been bereaved and they question their expertise' (Funeral Director)
>
> 'Very little in nursing and medical curricula about dealing with death' (Clinical Governance Co-ordinator).

Education could also be beneficial in directing appropriate referral of the bereaved to other services. Specialist service providers are often asked to see bereaved people who could have been treated more appropriately within a generic service, for example, primary care. They believe that professional education that includes raising awareness about the roles of other practitioners would be useful.

> 'I am not confident in the system getting people to the right person with the right skills at the right time and I don't think there is the infrastructure there to make sure people don't go down the wrong pathway going to mental health teams when they do not have a psychiatric disorder. Occasionally people will be referred inappropriately we would regard and too early. Often the initial response may be providing the GP with advice on what to say and monitor and on a framework of getting back in touch' (Consultant of Psycho-social Oncology).
>
> '...the knee jerk reaction as soon as there is a death or event that has led to a bereavement it seems that people think the thing to do is get the person referred. It can be like taking a hammer to crack a nut type of approach. So education on how people deal normally with bereavement, how do young people deal with loss in their lives without having to engage in counselling or other services' (Youth Counsellor).

There is already a variety of educational programmes, modules and training in existence that is being delivered by a variety of professionals in a variety of settings. Most are delivered to a specified group, for example hospice nurses, though increasingly work is being directed across disciplines. A range of education and training initiatives could be developed that are designed for specific roles and required competencies irrespective of professional group.

'At the moment there is slightly different training for the different professions. Multi-disciplinary training would help....there is a need to pull everything together' (Support Worker for Children and Young People, cancer support centre).

However, at present there appears to be uncertainty about competency in bereavement care at any level. A number of interviewees were closely involved with providing educational programmes. Hospice staff were particularly involved in training both internally and externally, possibly reflecting the view that this is where expertise in bereavement lies.

'All courses: introductory; support workers courses; professionals have something on bereavement and loss' (Practice Educator 1).

'I'm involved in education on bereavement care to a range of palliative care staff from untrained staff to medical staff. I teach on bereavement specific to children to same wide range of staff. In the long run the aim is to prevent abnormal grief reactions and to prevent the 'if onlys........' The training has been evaluated, but there is a need for feedback on what is useful to them' (Practice Educator 2).

'I have responsibility for the delivery of the training so that volunteers could have their training maintained' (Family Support Services Co-ordinator, hospice).

Provision from other sources is also in evidence.

Courses are individually orientated and taught through analysing what practitioners are doing regarding bereavement, analysing it and taking it forward' (Education Programme Leader).

'I provide seminars for other professionals who have a connection with death; nurses, carers, on a monthly basis. I do a talk about bereavement support and that talk is about how we can be better helpers when dealing with grieving people' (Funeral Director).

'I organised a seminar about bereavement...how we look after ourselves as staff as well as the person who has died and the relatives......the feedback was that people wanted more of this regarding bereavement care and what is expected' (Clinical Governance Co-ordinator).

Staff running courses and seminars on bereavement care or containing elements on bereavement care commented on their popularity and the high level of subscription attracted. This illustrates the commitment of practitioners to 'getting it right' and to having a long term positive impact on the experience of the family at the time of a death. Although there is

great willingness on the part of staff to learn they often encounter difficulties in obtaining funding from their employers to attend. Health board resources in particular are finite and their use for this type of training will depend on how the impact of bereavement and bereavement care is viewed by the organisation and the overall commitment to its improvement. However, education of staff may ultimately be a cost saving.

'I think there is quite a lot of education around, its the resources for people to access it' (Practice Educator 1).

'Education is nowhere near as costly as complaints; one will cost £10,000 if it goes to an independent review panel. People often say 'I'm not sending them on that training course, it costs £500 or whatever' but one complaint can cost so much more than that' (Chief Executive, national voluntary organisation).

As part of their roles in the development of bereavement care services in other parts of the UK, policy advisors who took part in interviews described the work they had done in disseminating the information they had produced. This took the form of workshops held at NHS Trusts across the country. A key focus was to facilitate the implementation of guidelines in practice and to allow staff the opportunity to network and share ideas. The value of networking and the sharing of ideas between practitioners is an important thread that runs through many of the themes in this study.

'In the workshops we get people to look at specific core elements and policy areas in the advice (When a Patient Dies) and think about what the barriers are in their Trust to achieving that. We look at practical solutions for them. It's been valuable for staff as it gives them an insight into ways to change or improve or establish their service' (Policy Officer).

'People needed to be able to share information and to have peer support. We started the workshops as a one off and we had the eighth yesterday. It really has proven very interesting and it is very rewarding because people share problems, they share solutions, they share best practice and this was something that disappeared when the market was first introduced and everybody became very guarded about their work. I am a great believer that if you give people the tools they will do the job. What we see as part of the role of the bereavement

89

officers in the hospitals is staff training for everybody involved in the process' (Specialist Health Policy Advisor).

Training has been identified, within local policy development, as a key role for bereavement officers or co-ordinators. In Scotland this has been a key part of the work of the hospital based Bereavement Co-ordinator interviewed who described providing programmes for all levels of staff, recognising the contribution of each person who may come into contact with bereaved relatives. There may be value for other organisations in having a dedicated individual who can co-ordinate educational activities across professional and organisational boundaries.

'We have been carrying out a training needs analysis for all staff, identifying what is currently available and developing training proposals and sessions to address and fill any gaps. For example, we have developed a new induction and continual training programme for our porters to take into account manual handling, health and safety and any other issues that come up for them relating to their role in laying out bodies or for relatives to come for viewings when our mortuary staff aren't on duty' (Bereavement Co-ordinator 1, hospital).

Practitioners, with experience of bereavement related work, often have ideas about how training and education programmes should be developed. They believe that courses and programmes should be delivered in a structured way and with relevance to the participants' situations and using the available evidence base.

'A professional approach to education should be taken with proper framing and validation of content' (Researcher 2).

'Good education, not just a wee bereavement course for a weekend, needs to be structured and quite powerful' (GP 3).

'I'm becoming increasingly aware that education and practice are not informed by research' (Head of Midwifery Education).

Others see value in less formal training with increased communication about bereavement between colleagues. Some who are regularly in contact with the bereaved but who feel that their training in this area is lacking believe that they would benefit greatly from some sessions providing them with practical advice.

90

'Our own training instructors should provide it but it would be good to get someone from outside to talk to us about it, someone who deals with it quite a lot. They could tell you how it should be done as well' (Ambulance Paramedic).

'Getting staff to feel more comfortable with it. Continual support for staff, not training, but encouraging them to not be afraid of it and to learn different skills and ways of communicating. It's all about communication and attitudes. Skilling up people to be more sensitive ...staff come across as insensitive because of their own fears and inhibitions' (Clinical Governance Co-ordinator).

Being realistic about death and bereavement is also important when providing education on the subject.

'...one of the things that is missing is the 'dirty element'. The midwifery text books have got lovely pictures of dead babies with clothes on looking really nice but the reality is different' (Head of Midwifery Education).

Those leading courses and programmes of education in bereavement care often believe that participants should be enabled to explore their own feelings and experiences of bereavement to help them to care compassionately for others. This enables people to have a greater awareness of how the bereaved can feel and what they may be experiencing. These types of sessions are acknowledged to be difficult to facilitate but appear to have an important impact on practitioners and their subsequent practice.

'Education required by professionals involved in bereavement care may need to begin with professionals confronting their own losses' (Researcher 1).

'What works well is small group work, no more than twelve and a mix of formal presentation of theories and research, and exploring experiences. It is important to build a 'safe' group within which people can feel comfortable about discussing personal experiences and emotions. Ground rules have to be established in order to build comfort' (Practice Educator 2).

'Lots of people bring their own issues of loss to these sessions. It is quite difficult to know how to pitch it if you don't know them and the groups are quite big. You can't help other people if you haven't come to accept your own death. It is very important on a professional level and a personal level. People develop self awareness of their own issues that they bring to a situation. You can't help

people unless you've worked through your own feelings and issues yourself' (Practice Educator 2).

'The pregnancy and loss module makes it real, starting from a basis that everyone experiences loss though not everyone has experienced the loss of a child or mother. Students explore their own losses and its up to them how much they discuss' (University Lecturer 1).

However, some education providers are concerned that the exploration of an individual student's grief is beyond the purpose of providing understanding about grief and loss.

'We get them to think about what it means to them, but they often want to talk about a particular bereavement that has happened to them. This can be difficult as we are not there to provide counselling. I get suspicious of why people want to do the course, that it may be to sort themselves out' (Education Programme Leader).

This may be due to course leaders having to make judgements about the range and extent of material that should be included in any programme and the time available to provide support. Formal evaluation of courses should enable education providers to be better informed about the long term value of participants exploring their own experiences.

Interviewees also stressed the importance of practitioners taking a compassionate approach to bereavement which may not be easy to teach, particularly if emotions and feelings are not part of a programme. Two, both involved in midwifery education, discussed their opinions about teaching people to be compassionate when caring for bereaved parents, siblings and wider families. Whether it is possible to teach or advise on this or whether there are some people to whom it comes naturally is an interesting debate.

'Though I feel that empathy is innate I think that you can teach sympathy and sympathetic attitudes and being with the person, how harmful platitudes are etc.' (University Lecturer 1).

'There's a concept called 'emotional intelligence' gaining currency certainly within medicine, nursing and midwifery and one of the things about that and one of my colleagues is doing a PhD on it and there is a debate as to whether you are born with it or whether we can teach you to acquire it' (Head of Midwifery Education).

92

Irrespective of point of view, a critical part of providing education and training in bereavement care is to ensure that the theoretical content of courses and seminars can be interpreted practically and used to the benefit of the bereaved. Course participants and seminar delegates must be able to identify: a) what their training needs are before the course commences; b) what their learning outcomes are; and c) how they can put their learning outcomes into practice. Interviewees have importantly identified increased confidence in caring for the bereaved in those who have had some education and training and a greater understanding of the emotions and difficulties that people face after bereavement. Consequently they are able to be more supportive of them. Some practitioners also believe that staff should be supported within their workplace to put the theory they have learned into practice. This has implications for who should or could provide mentorship to those less experienced.

'It is important that staff have support to put theory into practice and know where to find up to date information' (Project Manager, non-malignant palliative care).

'I think it does filter down to practice level because people previously haven't thought about it very much, haven't had time to think about their own feelings, didn't feel confident to support people. I get them to look at their own feelings and also some of the theories on bereavement. Theories can help us to understand why people cope the way they do. I link it with coping and communication skills, getting them to recognise what is normal for most people. The most important thing is to understand how people are feeling, that they need reassurance about how they feel, and getting people to recognise that they can be supportive' (Practice Educator 1).

'There are also good evaluations on the training. People report, on average, a 70% increase in their confidence, competencies etc' (Voluntary Sector Practitioner).

Staff in education must continually be assessing the methods they use to disseminate information and updates to practitioners. For some the internet or intranet may be the most simple and universal means of doing this, but some scepticism exists regarding the level of usage.

> 'Getting the knowledge round the whole hospital is important. Who's going to go onto a website to look at all that stuff?' (Clinical Governance Co-ordinator).

This may be due to a number of factors: time constraints; out dated computing hardware; poor skills in IT. Consultation with staff will be necessary to solve these kinds of difficulties and examine the most appropriate ways of keeping people informed of practice and developments in bereavement care.

Education in bereavement care for staff across the sectors appears to be viewed as important to developing policy and practice in bereavement care. However, the type of education and training is varied in nature and appears patchy in availability. As with bereavement care in general it may be that there needs to be some co-ordination of training courses, seminars, workshops and less formal training sessions at a local and national level. Those involved in education should be considering the level of course in relation to the degree of competency required to fulfil roles in caring for the bereaved. Practitioners at all levels across the statutory and voluntary sectors should have access to appropriate validated education wherever they are. Employers should also provide and encourage practitioners to use educational opportunities and be able to commit resources to improving bereavement care, which may actually result in reductions in overall costs.

3.6. The Bereavement Care Workshop

A further component of Phase 2 was the Bereavement Care Workshop held on the 6th July 2006. At the workshop further discussion of the issues and themes arising from the interviews took place and delegates had the opportunity to add their experiences and ideas to the discussion. The 85 invited delegates were drawn from a range of statutory sector, voluntary sector, governmental, research and education settings, mainly from within Scotland. Some had taken part in telephone interviews. The workshop was opened by Paul Martin (Chief Nurse for Scotland) and the scene set by Dr Colin Murray Parkes (Life President of Cruse Bereavement Care).

3.6.1. World Cafe: Emerging themes and issues

The conversations held between small groups of delegates during the World Cafe produced a large amount of ideas and creative thinking about the assumptions made within current bereavement care practice and policy that needed to be challenged. Ideas were also emerging on how to create change on these issues. Again, themes in common with those coming out of the literature review and the consultation and mapping study arose. The outcomes of the workshop are summarised below and are based on the facilitator's report of the event.

1. **The definition of bereavement care**:
    o it means different things to different people and each may have different needs;
    o bereavement care is about fostering independence in the context of grief as normal;
    o bereavement care not necessarily provided by family or faith group;
    o whether bereavement care helps or services are based on evidence.

2. **The purpose of a policy:**
    o multiple perspectives make developing a cohesive bereavement care policy difficult;
    o necessary to highlight importance of bereavement care;
    o necessary to encourage networking between practitioners;
    o determination of who will use a policy;
    o recognition of individual needs but also to address generic principles, e.g. risk.

5. **Normalisation:**
    o bereavement is a normal part of life;
    o need to promote self care;
    o professionals should never impose help;
    o challenge the notion that help helps and that sadness is always unwanted.

6. **Fundamental culture change:**
    o death is a taboo subject;

- o hidden impact of failing to discuss death;
- o normalisation needs fundamental culture change with open discussion;
- o include in core curriculum in schools and use media to discuss.

7. **Education and support for professionals:**
   - o important to have continuing high quality and appropriate education;
   - o challenge to assumption that professionals can cope;
   - o provide appropriate support.

8. **Bereavement as a public health issue:**
   - o people identified bereavement as a public health issue;
   - o need campaign to educate the public about bereavement as normal;
   - o population approach to prevention of complicated grief.

9. **Research:**
   - o important to collect evidence about prevalence of difficult bereavement;
   - o need to know the scale of challenge to inform service development.

10. **Co-ordination of information, resources and expertise:**
    - o services fragmented and disparate;
    - o systems should facilitate sharing of knowledge;
    - o need to identify a central resource for bereavement.

3.7 Areas for Action

Six key areas were identified for action by the workshop participants and considered in detail by delegates at the Open Space event:

1. Encouraging culture change along the lifespan;
2. Education and training (health/care worker)
3. A national framework for bereavement care
4. Intervening in schools
5. Research
6. Information and co-ordination

1. Encouraging culture change along the lifespan

This is a challenging action but can be achieved through a range of strategies and building of alliances between groups to challenge present stigma and taboos surrounding death and bereavement. A strategy should draw on previously successful culture changing campaigns, for example, those aimed at smoking and mental health and involving organisations and institutions such as health care, schools and the media. Such campaigns can raise the profile and might even focus on specific issues such as gender and bereavement. A survey of public attitudes on death and bereavement may be helpful to gain insight into the perceived scale of stigma.

2. Education and training (health/care worker)

A structure for professional education and support which spans foundation to specialist level should be available. However, the key is identification of the needs of professionals and complementing what is already available to enable the development of integrated approaches and avoid duplication. The structure should have a foundation level that is aimed at everyone who has contact with the bereaved (across the lifespan); an intermediate level which would be aimed at specific roles and advisors; a post graduate level which would target those involved in areas associated with complicated grief.

Provision of support for staff caring for the bereaved should be facilitated through good communication with seniors and providing specialist interventions according to need.

3. A national framework for bereavement care

Although there were many unanswered questions about the objectives, impact and evidence for a national framework, the outcome was a clearer picture of how it might be developed and what it might contain. The framework should be rooted in practice and experience; be formed and driven by a small group of 10-15 key stakeholder representatives; have focused and clear evidence based outcomes; a long term plan with 8-10 objectives/sub-strategies.

A national framework could address current gaps in the bereavement picture, namely consistency of approach, co-ordination and quality of information. It should, if possible, be simple and brief, involve practitioners and the bereaved; and have links to other strategies, for example, quality assurance frameworks. The framework could impact positively on the health and well being of individuals, families and the economy.

4. Intervening in schools

The main thrust of this action would be centred on introducing death and bereavement to curricula at pre-school, primary and secondary school levels. Such introduction could enhance normalisation and culture change. Achieving this change requires input from many agencies, for example: local education authorities, schools, teacher education, social services, health services, voluntary sector, parents and communities and the Children's Commissioner. It could be achieved through this multi-agency approach, development of a co-ordinator role, linking to mental health and emotional well-being and ensuring equality of provision across schools.

Successful achievement of this action could open up communication about bereavement, lessen taboos, improve general health, reduce pathology and dysfunctional grief responses and thus reduce impact on services at a later stage.

5. Research

There was a desire to see co-ordination and development of high quality, robust research and evidence to inform the development of bereavement care practice, policy and a national framework. However, currently activity in this area is disjointed across Scotland and practitioners had little opportunity to carry out research in their roles. An internet based bereavement research forum was suggested with a longer term goal of developing a bereavement research centre for Scotland.

6. Information and co-ordination

The lack of co-ordination of resources and information about bereavement care was a major theme of the workshop. A need was identified for some

form of central information point to support all: relatives; service providers and the public. This could provide a range of information: research; practice innovation; expertise and experience; practical and legal information; access to services; other general information.

The central information point could be internet or community based and its existence publicised widely. It could also become part of other sources of information, for example, NHS 24, NHS Direct, e-library and managed knowledge networks. Initially the resource could be developed using existing resources, for example, the Scottish Executive website that already links directly to other organisations.

3.7.1. Workshop conclusions

The workshop created a unique atmosphere for development of ideas and thinking about bereavement care in Scotland. Participants were astonished by the level of expertise, knowledge and experience in the room and also at the extent to which values, priorities and ideas were shared across the disciplines. How to enable this to be made more accessible and co-ordinated was a key question raised throughout the day.

Furthermore there was acceptance of the complexity and cross-cutting nature of bereavement care. There was also a commitment to development of some form of central policy to drive practice that takes account of the diversity involved and does not dilute its importance. Participants, as practitioners involved in the care of the bereaved, were keen to have their voices heard. There was a genuine groundswell of support for the opinion that change was necessary across all sectors to improve bereavement care provision. This was matched by a commitment of intent to make this change happen.

3.8 Validation of areas for action

Throughout this study of bereavement and bereavement care, Phases 1 and 2, linkages are discernable between the key messages, themes and areas for action that have emerged. It has become apparent that on examination of these areas for action, identified by delegates at the

Bereavement Care Workshop, each contains a variety of key messages and themes from the other parts of the work. This commonality gives validation to the outcomes of each part and assurance that the points for action are 'real' and are the things of importance indicated in the literature and by those who provide bereavement care in Scotland. Table 6 below displays the areas identified for action in the Bereavement Care Workshop and links each to themes from the consultation and mapping and key messages from the literature review.

Table 6. Mapping of action points arising from the Bereavement Care Workshop, to the themes derived from the consultation study and the literature review

Action points arising from bereavement workshop	Themes derived from the consultation and mapping study	Key messages arising from the literature review
1. Encouraging culture change along the life span.	6. Co-ordination and communication 8. Guidance 9. Education	1. Grief is a normal process 2. A compassionate approach 8. Cultural and spiritual factors 6. There are a range of information needs at locally and nationally 11. Education for health and social care professionals 10. Standards, policies and guidelines
2. Developing education and training for service providers.	9. Education 6. Co-ordination and communication 7. Follow up for the bereaved	11. Education for health and social care professionals 1. Grief is a normal process 8. Cultural and spiritual factors 4. Interventions should be tailored to need 2. A compassionate approach 3. Risk factors for abnormal responses are amenable to assessment 5. Follow-up has been identified as important 9. A co-ordinated approach to bereavement and bereavement care
3. Building a national framework for bereavement care.	8. Guidance 3. Equitable service provision 6. Co-ordination and communication 2. The level of expertise and enthusiasm 7. Follow up for the bereaved 5. Range and type of approaches to bereavement 4. Awareness of the impact of grief, loss and bereavement	10. Standards, policies and guidelines 12. Research into bereavement and bereavement care is essential 6. There are a range of information needs locally and nationally 8. Cultural and spiritual factors 3. Risk factors for abnormal responses are amenable to assessment 5. Follow-up has been identified as important 7. 'Hidden' socio economic factors 9. A co-ordinated approach to bereavement and bereavement care

4. Intervening in schools to enhance understanding of death, dying and bereavement.	9. Education 2. The level of expertise and enthusiasm 8. Guidance 6. Co-ordination and communication 3. Equitable service provision 1. Burden of bereavement	11. Education for health and social care professionals 1. Grief is a normal process 10. Standards, policies and guidelines 8. Cultural and spiritual factors 9. A co-ordinated approach to bereavement and bereavement care
5. Co-ordination and development of research activity.	8. Guidance	12. Research into bereavement and bereavement care is essential 10. Standards, policies and guidelines 13. Establishing a *Centre for Bereavement Care* 3. Risk factors for abnormal responses are amenable to assessment 5. Follow-up has been identified as important
6. Information: co-ordination and dissemination.	6. Co-ordination and communication 2. The level of expertise and enthusiasm	13. Establishing a *Centre for Bereavement Care* 6. There are a range of information needs locally and nationally 12. Research into bereavement and bereavement care is essential 3. Risk factors for abnormal responses are amenable to assessment 9. A co-ordinated approach to bereavement and bereavement care

NB. This map highlights areas where clear cross referencing is apparent. However there may be other elements of cross-cutting relationships between the different phases of data collection that are implicit in nature.

Chapter 4. Discussion

A considerable amount of engagement with bereavement and bereavement care exists within the statutory, voluntary and independent sectors in Scotland. This was clearly demonstrated by the recruitment process adopted in this study and the range of practitioners and others who agreed to participate in interviews and in the Bereavement Care Workshop.

Snowball sampling found that, over the eleven weeks available, new names were continually suggested and there was little repetition. This process, we believe, could have continued beyond the time limit and gives some indication of the large number of practitioners and others involved in bereavement care as part or the whole of their job. The number of delegates who attended the Bereavement Care Workshop was also an indicator of the degree of involvement. Their engagement with the discussions on the day and the enthusiasm conveyed in many of the interviews conducted also indicates the importance which practitioners award to bereavement care and their willingness to champion the cause of the bereaved. Of course, within the time scale available it is not possible to state categorically that the sample identified in Chapter 3 is representative. However, response to the results of the literature review and interviews would suggest that the messages elicited are representative of this field and may be actionable. The six action points taken from the Bereavement Care Workshop are discussed here in terms of their application to the future development of bereavement care services in Scotland.

Whilst some additional reference material is incorporated, the literature review completed for Phase 1 contains significant underpinning work for this discussion.

4.1. Encouraging culture change along the life span

Through the latter decades of the 20th century death, dying and bereavement are topics that are becoming hidden from everyday life even though they are something that everyone will experience (Johnson 2004).

With our transition to the 21st century we need to encourage discussion of how death, dying and bereavement can be absorbed into life in a way that makes them more acceptable (Arnason and Hafsteinsson 2003). Greater awareness of them as 'unexceptional' phenomena could enhance health and well being and also allow communities to be more supportive of the bereaved. Changing perspectives on bereavement have resulted in a move to recognise that loss through death is not something we 'recover' from but something that we adapt to and build into our continuing lives (Stroebe and Schut 1999). At times, however, there are some individuals who will not be able adapt to their loss and may need further help and support.

Education of the public has a large part to play in enabling this type of culture change. There may be a place for media campaigns and public service broadcasting as has already taken place in raising awareness of, for example, anti smoking messages (National Health Service 2006) and mental health issues (Scottish Executive 2006). Recent topics in the press concerning bereavement, for example, in connection with mountain top memorials have attracted large amounts of debate and may signify a desire in people for more openness and free discussion (BBC 2006). Whilst a diverse range of information is available, locally and nationally, this is often directed at the bereaved or those working in areas where they may come into contact with the bereaved. For a more general distribution of messages relating to bereavement as a normal process the use of media such as television and the internet are the obvious places in which to open up the subject.

Irrespective of any fostering of culture change related to the 'normality' of bereavement, there is evidence that five to ten percent of bereaved people are unable to adapt normally to their grief and will need some professional intervention (Centre for the Advancement of Health 2003, Schut et al. 2001). These complicated grievers will often need help and support beyond information and advice. However, in general, the level of provision will depend very much on the individual and his or her needs, many only requiring some validation of their response and fewer requiring

the use of specialised mental health and psychological services for complicated grief reactions and depression.

Practitioners interviewed in this study have described providing services for the bereaved in terms of grief as a normal process, allowing people to recognise their needs and seek help accordingly. Nevertheless, because bereavement can have wide reaching consequences for society and may be implicated in such things as poor mental and physical health (Parkes 2001), anti-social behaviour and teenage pregnancy (Ribbens-McCarthy and Jessop 2005), there may be a need for grief and bereavement to be examined in terms of being a public health issue. The inclusion of bereavement on the public health agenda may result in a cost saving to society as well as highlighting the need for research activity and service development. More general awareness of deleterious outcomes from bereavement, particularly related to some types of death, could be to the benefit of society as a whole.

One of the areas of bereavement that appears to receive less attention than others, is bereavement in older people. Why this should be so, when the majority of the bereaved would fall into this category is not possible to explain. Field et al (2005) also noted, in respect of palliative care provision, that there was insufficient evidence on which to base a judgement about the needs of older bereaved people. This mirrors the experience of the researchers in both phases of this work who identified a lack of positive literature on older people and bereavement, and limited direct reference to the needs of older people in interviews. It may be the case that bereaved older people are implicit in all of the bereavement care that includes adults. It may also be the case that uncertainty exists around where "older" is in chronological terms. However, having greater understanding of bereavement and bereavement care for older people may be essential as our population ages, secularisation increases and support networks diminish.

If the recognition of the impact of bereavement is strengthened, services (including information and advice) need to be available to meet the needs of the bereaved. In Scotland, some co-ordination and communication between practitioners and others appears to be necessary to achieve this

end. When people have been identified or encouraged to recognise the point at which they have a need, there will be a requirement that a service will be available for them. At present services are not always available in all areas of the country or for people bereaved through a variety of modes of death. Co-ordination of service development (across all sectors) to ensure equitable provision could follow the development of national policies for bereavement care. Locally based guidelines that are built around a national framework and consisting of a range of services would encourage organisations and practitioners to provide services tailored to need or to guide people to the most appropriate service.

The door for such development would appear to be already open as those engaged in bereavement care have demonstrated a real desire to do their best for the bereaved and to have a role in promoting discussion of bereavement and its consequences. Concomitantly they have expressed a need for education and training to improve knowledge and skills. Building such programmes around grief as a normal process and the implicit compassionate approach are instrumental in enabling professionals to understand the implications of grief and bereavement and to recognise how they themselves react. Such programmes could enable them to help the bereaved to have a greater understanding and acceptance of their emotions and to open up discussion with people, patients and clients before, and after they become bereaved.

People have varied reactions and diverse needs following the death of a close family member or friend (Berzoff and Silverman 2004). With Scotland becoming increasingly multi-cultural there are many different interpretations of what may be normal or abnormal surrounding death and bereavement. There is now more need than ever for the wider community to have some awareness of each others' differences and to be encouraged to be open and supportive when necessary (Parkes et al. 1997). Increased knowledge of the variety of cultural needs, prior to, at death and beyond, for families and individuals is instrumental in development of services that are culturally competent (Chaplin 2003).

Throughout this study the need to address the stigma and taboos that surround death and bereavement has been apparent. There is a belief

that the open discussion of the effects of bereavement, the needs of the bereaved and of the services available for the bereaved will enable greater capacity for the bereaved to accept their losses. A more understanding and supportive community structure could, in many cases, negate the need for professional intervention for the bereaved.

4.2. Developing education and training for service providers

A number of factors have fed into the need and desire for professionals involved in the provision of bereavement care to build up their knowledge and skills in this area: the perceived burden of bereavement on services; the development of care standards that include bereavement care (Macmillan Cancer Relief 2001); and the evidence emerging from research in bereavement. The outcomes of this study, particularly Phase 2, have revealed the need for a tiered system of education provision for all levels of staff that are likely to be involved with the bereaved. Figure 4 below illustrates the levels of educational provision that practitioners have said should be available to staff across the sectors. This model is not unique to bereavement care and mirrors that enacted by NHS Education for Scotland in relation to another issue that cuts across disciplinary boundaries, namely healthcare associated infection (West et al 2006).

Figure 4. Tiered model of education for service providers

Specialised clinical and counselling courses

Post basic training: specific courses and modules; CPD.

Role specific - included in undergraduate nursing, medical and social work curricula

Foundation level - short courses, raising awareness of grief as normal
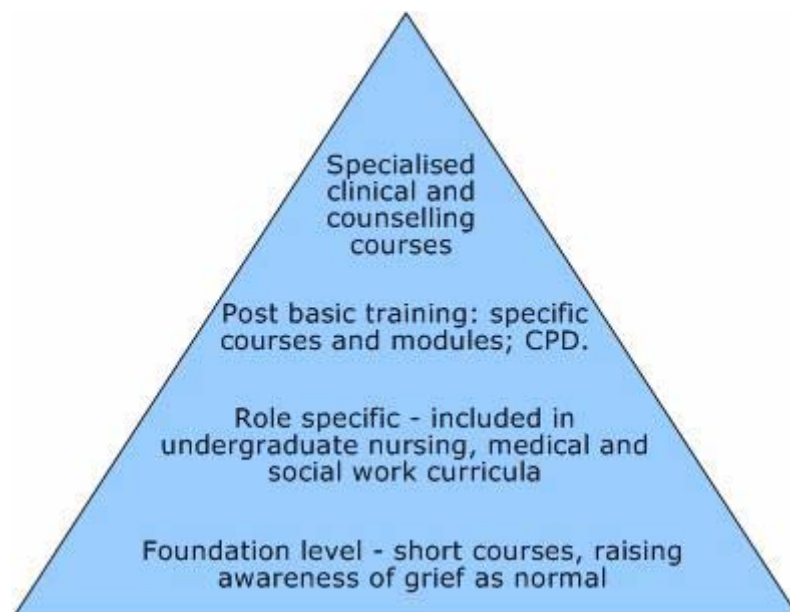
Participants in interviews and at the Bereavement Care Workshop believe that education and training should be provided to all levels of staff across the sectors that may come into contact with the bereaved in the course of their work. In, for example, a large general hospital where there may be several bereaved people affected by each death (The Nucleus Group 2004) at any one time, there is potential contact with a variety of levels of staff. Training should be provided from a fundamental level for those who have limited but important involvement with the bereaved (hospital porters and mortuary staff) through those ward based staff with more direct contact, to skilled specialist practitioners who provide services addressing complicated grief reactions.

Practitioners also believe that bereavement care, though poorly addressed in undergraduate courses for nursing, medical and social work students, should be given more prominence with specific modules developed to address the lack of knowledge and understanding of grief and its consequences. For those who may have developed an interest or enthusiasm in the topic, or with a higher level of involvement with the bereaved (clinical nurse specialists, social workers, voluntary sector workers, palliative care specialists, mental health practitioners, midwives and health visitors) there should be accessible higher level education and training available that may contribute to continued professional development. Specialised clinical and counselling courses for those providing higher level medical and bereavement care should also be available to provide care for those who have more complicated needs. All staff, from whatever sector, should be given opportunities to develop their skills, knowledge and self awareness to enable them to feel confident about the care and support they provide for the bereaved (Department of Health 2005). However, this demands that a relevant raft of programmes is available nationally.

Models for education and training have become apparent in this study, especially within hospice and palliative care and in midwifery for all levels of staff. There are many aspects of this type of approach that will have resonance in other areas and could be tailored to the needs of staff in different settings. In particular, many recognise the need for course

participants to be able to explore their own experiences and emotions regarding bereavement to increase understanding of others and to promote a compassionate approach to dealing with the bereaved (Wass 2004, Corr et al 1991). Elements of the first action point, in respect of raising awareness of grief as a normal process, should also come into play within educational provision. This may also encourage staff to allow the bereaved to adapt to their loss without intervention in the period surrounding the death.

Education and training packages should also incorporate up to date available evidence, particularly in relation to risk assessment, interventions and follow up for the bereaved which could have a significant impact in health and social care settings (Wimpenny et al 2006, Centre for Advancement of Health 2003, Stroebe et al 2001).

4.3 A national framework for bereavement care

The Gold Standards Framework Project on community palliative care (Macmillan Cancer Relief 2001) and Clinical Standards for Specialist Palliative Care (Clinical Standards Board for Scotland 2002) have been a base from which many palliative care services in Scotland have built their provision for dying patients, their carers and families. Bereavement care is included in these standards of care and some practitioners in this study have embraced the opportunity to extend their service to the family before, during and after the death of the patient.

Services have evolved to suit local need with teams being responsible for the development of an appropriate bereavement service in their area (Macmillan Cancer Relief 2001). Practitioners, often enthusiasts for bereavement care, have been at the forefront of the development of services that may in fact be suitable models for services delivered to the bereaved in other situations. Gaps in service provision for bereavement care have been identified by interviewees and by national bodies (NICE {National Institute for Healthcare and Clinical Excellence} 2004) in a number of areas including general hospitals, emergency services and community care. Hospice and palliative care practitioners have indicated that the type of service they provide could be transferable to other

situations, either in whole or in part, to the benefit of the bereaved and satisfaction of care providers. However, there may be some limitations imposed due to available time and resources.

A tiered model for the delivery of bereavement care appears to be an option. Like the model for education provision, this model includes everyone, in all sectors (including volunteers), that may come into contact with a bereaved person (see Figure 5 below). This may be an appropriate model from which to build a policy or national framework for bereavement care, although it will probably require a high level of co-ordination, possibly from a central body. Examples of such co-ordination are apparent in other parts of the UK relating to bereavement care in health care settings, predominantly hospitals. These approaches have usually arisen in response to the inquiries into the care of children receiving complex cardiac surgery at Bristol Royal Infirmary (Kennedy 2001) and organ retention at Alder Hey Hospital (Redfern et al. 2001). However,

Figure 5. Tiered model of service provision

Psychiatrist
Psychologist

Counselling services,
mental health
services

Bereavement co-ordinator,
information providers, helpline
staff, specialist practitioners

Nurses, doctors, allied health
professionals, social workers, undertakers,
faith representatives, emergency services

Hospital porters, mortuary staff, receptionists

they appear to have moved beyond these to incorporate a broader remit in respect of co-ordination of bereavement care within particular local contexts.

Informants in this study have highlighted the importance of providing services to the bereaved equitably across Scotland and inclusive of all, for example, those with particular cultural or spiritual needs, or socio-economic status. Any standards and guidelines developed locally should take account of these factors in the communities they serve. For example, to date little has been done to determine levels of bereavement care needs within deprived communities (Richardson and Pearson 1995) or assess the economic impact of bereavement, which are believed to be extensive but difficult to ascertain. Additional research is required to determine the effects of bereavement on families and individuals and the level of unmet need in, for example deprived or ethnic communities.

The study has also found that bereavement care is provided by many practitioners at three definitive stages: pre-bereavement, at the immediate time of the death and in the period following the death. Standards and guidelines developed locally could detail the provision that is available at each stage. The time of involvement will depend to a large extent on the nature of the service provided and the needs of the bereaved person. Agreed standards and guidelines could reflect the level of bereavement care required within the community that can be realistically provided.

The extent to which the palliative care model of follow up can or should be achieved in other services should be considered. A wide range of approaches to bereavement care are apparent from study respondents, from risk assessment alone, through group support to specialised counselling and mental health services. Most services are able to provide the whole range but paths of referral should be built into the guidelines to enable all the needs of the bereaved to be addressed on a local basis wherever possible. Such local provision is welcomed by the bereaved and is reflective of the issues raised in the government white paper, 'A National Framework for Service Change in the NHS in Scotland' (Scottish Executive 2005).

Practitioners in certain roles, for example the emergency services, will have little or no contact with the family before the death though it may be feasible for them to carry out a brief risk assessment and relay

information about risk to an appropriate person who could provide follow up. This joined up approach could be advantageous for the bereaved so that they are not 'lost' across the boundaries between stages of bereavement care.

A number of practitioners have described the value of carrying out anticipatory grief work that paves the way for the bereaved person to adapt to life without the person they have lost, although the nature of such work is contentious (Fulton et al. 1996). Pre-bereavement work often involves some form of risk assessment, whether on an informal basis or in a structured way. There are advantages and disadvantages of both methods. Phase 1 of this work, the literature review, concluded that there was general agreement with the need for assessment of the bereaved to identify those most at risk of having complicated grief reactions though no clear evidence exists for how this should be carried out (Wimpenny et al. 2006).

Many generic and bereavement specific assessment tools are available though they often confound coping with loss with other symptoms i.e. psychological distress. The main focus of measurement should be on the ability of the person to cope with their loss in terms of grief as a normal process and most risk assessment tools do not reflect this clearly (Stroebe et al. 2004). However, there will be some benefit for the bereaved if in some way their risk is measured and appropriate action taken when risk factors are identified. Age, type of death, previous bereavement experiences, social support, characteristics of the bereaved person, and relationship with the deceased are key criteria that may be useful in identification of those who may require additional follow up and support (Wimpenny et al. 2006).

Policy, standards and guidelines should also address the dissemination of information to the bereaved and to service providers. Good quality literature at each level of provision should be available and accessible. The availability of, for example well written online and helpline resources, is essential for guiding people appropriately through their bereavement. In addition such resources could be produced centrally and adapted locally and assist in co-ordinating information provision in Scotland. This would

also ensure the provision of appropriate information for the bereaved and be a means of ensuring the quality of what is available.

Finally, as with any development of guidance or standards, those for bereavement care should have a foundation built from current evidence. It is also important that such guidance identifies areas that require further research so that gaps in service provision can be addressed in Scotland.

4.4 Intervening in schools

Around 2% of children under 18 years of age in the UK have been bereaved of a parent and many more are affected by the loss of a grandparent, sibling, classmate or teacher (Lowton and Payne 2004). Interviewees in this study have also voiced concern about death, dying and bereavement being concealed from the eyes and ears of Scotland's children. They warn that this ignorance may lead to increased levels of complicated grief reactions when they are faced with losing someone close to them or when they are faced with death in their working lives (for example as members of emergency services, nurses, doctors, and social workers).

The inclusion of death, dying and bereavement in school curriculum could help to dispel myths and clarify the realities for children. Schools may become involved with addressing bereavement in one of two ways: teaching children about death, dying and bereavement; and providing support to bereaved pupils, parents and staff members (Ribbens-McCarthy and Jessop 2005).

Little up to date information about the issue of bereavement within Scottish schools exists, although Scottish Executive education policy does recognise bereavement to be a significant challenge for some children (The Scottish Executive 2005). The Scottish Executive funded Learning and Teaching Scotland website (Learning and Teaching Scotland 2006) also contains information about bereavement and loss, mourning, likely responses, what families can do and carries links to organisations like Cruse Bereavement Care Scotland. It appears that consideration has been given to these topics within Scottish education services. However, to

what extent this has been achieved is unclear and would require further research to determine.

Participants in the interview study believe schools to be the appropriate place to begin educating children about end of life and how they may feel when someone close to them dies. Some practitioners interviewed, particularly in palliative care, carry out a large amount of work supporting bereaved children and believe that raised awareness would mean greater understanding of their situation and emotions. For those children who have experienced loss and grief there are education programmes available that have been used by some practitioners interviewed, for example, Seasons for Growth (The Notre Dame Centre 2006). Choices exist for schools on whether death, dying and bereavement are taught as a topic on their own or within a larger subject heading. There may be opportunities to normalise the bereavement experience if it is brought into a variety of subjects, for example, history, social subjects or science (Ribbens-McCarthy and Jessop 2005). Some practitioners interviewed are already involved with schools and are having discussions with children about these issues. Others have no involvement and as yet are unclear about how an approach could be made but recognise the potential value of providing children with information.

Teachers cannot be expected to be experts in bereavement, though they do have long standing relationships with their pupils through which they can discuss sensitive issues. Doing so with the input of those who are involved with the bereaved in the course of their work may be the most appropriate way to help children to realistically understand death, dying and bereavement. Despite this use of experts, the inclusion of end of life issues in teacher training within the context of being part of life would be important to achieve in Scotland and could be an integral part of any national bereavement policy. This type of learning may also be instrumental in helping teachers to provide bereavement support to the wider school community.

Local standards and guidelines should identify resources for teachers and appropriate children's literature of which there is a significant range

(Lowton and Payne 2004, Servaty-Seib and Hayslip 2003). Appropriate lines of referral for teaching staff who want support for themselves or others in coping with a bereaved pupil, parent or fellow staff member should also be available. Secondary school pupils, as adolescents, may be in particular need of support which is ongoing (Lowton and Payne 2004). Children spend a significant amount of time in school and build up trusting relationships with school staff. Teachers will undoubtedly have to support children through losses in their lives and have a requirement for the training and support to carry out this part of their role well. Professionals involved with bereavement care as part of their work are an obvious resource that they should be able to call upon. Developments in bereavement care in Scotland should take place with consideration of the important role that schools can play. Although not identified by interview participants, literature indicates that there is also the need to address bereavement in other educational settings, such as further and higher education (Sandler et al. 2003). It is often in later teenage years that children encounter the loss of a significant family member (often grandparents) and the extent to which this impacts on their academic achievement is unknown but should be considered more fully.

4.5. Co-ordination and development of research activity

'The integration of research and practice has to be addressed at all levels within an organisation; from policy statements to procedure manuals and from managers, educators and clinicians to support workers within the framework of the management of change' (MacGuire 2006).

Delegates at the Bereavement Care Workshop would probably endorse the above statement and urge practitioners to pursue their research interests as up to date research into bereavement and bereavement care is fundamental to the development of services that will meet the needs of the bereaved in the future. However, not all interviewees necessarily viewed research as a priority in developing the service. Such views of research are possibly based on the premise that there are already many aspects of bereavement care that can be addressed and which are evidence based (although not high level in evidence-based practice terms)

and until these are addressed why do more? Despite this many practitioners in Scotland indicated that they have interesting practice based ideas and a desire to be able to do their own research. In this regard time and funding are seen as the main barriers to their ability to pursue these interests. There are also other barriers reported such as perceptions of harm to the bereaved from researchers and difficulties in defining terms commonly used around bereavement (Payne and Field 2004, Stroebe et al. 2003).

Co-ordination of research activity was identified as necessary and practitioners voiced backing for the establishment for a forum or Centre for Bereavement Care as suggested by Phase 1 of this research. One centre already exists in Victoria, Australia (others are also in the early stages of development in England and Wales) and may be a model on which a Scottish centre could be developed (Australian Centre for Grief and Bereavement 2006). This Centre carries out a number of functions in relation to grief and bereavement including running a professional education programme and a counselling service for the bereaved. Within the research network of the Centre links are provided to research journals and websites and practitioners can join a mailing list for people interested in grief and bereavement work.

Overcoming the barriers to research and development of a centre is an awareness raising issue concerning those professionals involved in the development of bereavement care in health and social care services. There must be recognition of, and engagement with, bereavement as an important factor to be addressed within the communities served. Only when this has been achieved can practitioners utilise such a centre and be given the time and funding that they require to carry out the research on which the service can be developed.

Possible roles regarding research of a Centre for Bereavement Care in Scotland could be: maintenance of a database of ongoing relevant research projects and findings; development of a discussion forum; provision of information on research methods; provision of information on professional development opportunities regarding research. Participants at the Workshop perceived that this need not be an expensive

116

undertaking and could be something that a collaboration of enthusiastic bereavement care practitioners could develop and publicise and be e-based.

4.6 Information co-ordination

A call for grey literature in Phase 1 of this study uncovered a wide range of information materials available to the bereaved and to bereavement care service providers. The quality of information contained in this range of materials was variable and often outdated. The bereaved and service providers for the bereaved have a right to be able to access information that they can trust to be up to date, informed by up to date evidence, and to convey the important things that they need to know.

Strategies for information sharing are most useful when developed jointly (Scottish Executive 2002), for example, with local authorities, the bereaved, bereavement care providers and the voluntary sector. The possibility of involvement of a central body or Centre for Bereavement care again arises here. There is potential for such a centre to become involved in the collection and dissemination of information and also in signposting people to appropriate resources for their needs. The resources guide of the Australian Centre for Grief and Bereavement can be used as an example here (Australian Centre for Grief and Bereavement 2004). It contains mainly books about bereavement experiences and reactions, many directed at children. In Scotland there may be a need for more extensive information about, for example, organ donation, Procurator Fiscal responsibilities, research activity, and emotional responses. There is also potential in developing a type of Managed Knowledge Network (NHS Education for Scotland 2006) which could also serve this purpose for up to date, quality information for practitioners in all sectors and facilitate linkage and networking between individuals and groups, that are at present working in isolation.

Integral to a co-ordination role should be quality assessment of material that could be included in a central database. The use of a framework for assessment of information has been developed in many health and social care settings and could be applicable to provision of information for the

bereaved and others. The framework could include such things as: relevance; evidence based; acceptability to the reader; equity and accessibility (Bowling 1997). Publicity of the facility will also be part of the co-ordination role ensuring that its existence is known to all practitioners. An internet based resource would appear to be the most appropriate means of addressing this potentially large logistical operation where it can be linked with other relevant websites and remain relevant and up to date. Again this may be organised through collaboration between a consortium of groups which may also be the most cost effective method of information provision and dissemination.

4.7 Mapping to Phase 1, literature review

The mapping of interviewees' priorities for carrying out bereavement care in Scotland with the key messages from the review (Phase 1), was in general alignment with the themes extracted from the interview study and discussed above. However, the ranked ordering of the messages as priorities for practice produced some anomalies. The importance of taking a compassionate approach was ranked highly, though not identified as a specific theme arising from the interviews. This is something that comes across implicitly throughout the interviews with many interviewees, in their expressed desire to do their best, conveying a sense of compassion and empathy for the bereaved. Some factors that were lower ranked, for example, development of standards, policies and guidelines; a co-ordinated approach and research for service development featured strongly in the interview data and were major outcomes of the Bereavement Care Workshop. Lowest ranked in people's order of importance was establishing a Centre for Bereavement Care though this did feature highly in the other components of Phase 2, particularly the Bereavement Care Workshop.

It is unclear why these differences have arisen, though it may be that people were prioritising according to what they thought they were able to address in their role rather than with a wider perspective. However, the interview questioning did ask people to take a personal perspective and/or to reflect the views of their organisation. Taking a national perspective is

difficult for some practitioners working in isolation and reflects the need for a more co-ordinated approach to bereavement care as highlighted in the interview study and Bereavement Care Workshop.

4.8 Concluding remarks and recommendations

Phase 2 of the research into bereavement and bereavement care in Scotland has uncovered significant engagement of service providers and others across the sectors with bereavement and bereavement care. Whilst a wide variety of thoughts and opinions were gathered from interviews and from the Bereavement Care Workshop there is, we conclude, a significant degree of commonality across key themes and areas identified for action that have arisen throughout the two phases of study as identified in Table 6 on pages 101-102.

The study has found many examples of committed work in the development of bereavement care services in both statutory and voluntary sectors that provide meaningful support to the bereaved. Evidence of effectiveness is however limited in respect of service provision and some evaluation of existing and future service provision would be useful. This might also include evidence of effectiveness of interventions, which at present is limited.

Discussion with the bereaved could also be undertaken to determine if their needs are being met by existing and future developments. Building in evaluation from the outset of any change will help to shape future provision and gather important on-going data. There is also a need to identify the level of impact of bereavement on services, for example, in primary care, where it would appear to be driven by a range of factors other than need, which is largely unknown. As bereavement is implicated in increased morbidity and mortality it would be essential to establish the use of services in all sectors and the health and social needs of the bereaved. Whilst most bereaved people work through their grief (90-95%) with support from family and friends, it may be that as many as 30% in the UK may seek professional support at some point and that most will contact their GP (Lloyd-Williams 1995).

Changing social support mechanisms in society have contributed to the need for GPs and other primary care staff to be able to distinguish between 'normal' bereavement responses and bereavement related disorders and to support and refer people who have difficult grieving experiences (Wiles et al. 2002). The extent of this engagement in primary care is unknown and planning of future service provision for the bereaved will be difficult as long as the amount of need within the population is unknown. Additionally, the level of support offered by the voluntary sector is considerable (estimated at up to 80% of all bereavement care) and should be seen as crucial to on-going policy and practice development. Without such provision, it appears to us, there would be limited services (information, advice and support) for the bereaved and others. Therefore any future developments in practice and education need to engage with these groups to ensure appropriate linkage and co-ordination can be achieved and expertise made available. Such linkage could, we have argued, be accommodated within a tiered model of service provision and education.

In summary, practitioners and those engaged with bereavement and bereavement care have identified six areas for action. These areas are consistent with the literature review and the consultation and mapping process that have been undertaken. Therefore there is considerable consensus, across a broad range of evidence, on the issues which need to be and can be addressed. From our researchers' perspective the development of a national framework would appear to be the most useful starting point. This can be used to build local initiatives, incorporating all the important factors involved in providing a bereavement care service, relevant to the needs of a particular community. This would also address equitable provision across the country that would reflect the diverse social and cultural needs of Scottish society in the early 21st century.

References

ARIES, P. (1983) *The Hour of Our Death.* Oxford: Oxford University Press.

ARNASON, A. and HAFSTEINSSON, S.B. (2003) The revival of death: expression, expertise and governmentality. *British Journal of Sociology,* 54(1), pp. 43-62

AUSTRALIAN CENTRE FOR GRIEF AND BEREAVEMENT (2006) *Grief research network.* [online] Available from: http://www.grief.org.au [Accessed 08/29 2006]

BALK, D.E. (2004) Recovery following bereavement: an examination of the concept. *Death Studies,* 28(4), pp. 361-374

BARRIBALL, K.L., CHRISTIAN, S.L., WHILE, A. and BERGEN, A. (1996) The telephone survey method: a discussion paper. *Journal of Advanced Nursing,* 24(1), pp. 115-121

BBC (2006) *Mountain memorial storm gathers.* [online] Available from: http://news.bbc.co.uk/1/hi/scotland/4242576.stm [Accessed 08/25 2006]

BERZOFF, J. and SILVERMAN, P., eds. (2004) *Living with Dying: A Handbook for End of Life Healthcare Practitioners.* New York: Columbia University Press.

BLACK, D. (1998) The dying child. *BMJ (Clinical research ed.),* 316(7141), pp. 1376-1378

BLACKTOP, J. (1996) A discussion of different types of sampling techniques. *Nurse Researcher,* 3(4), pp. 5-15

BONANNO, G.A. and KALTMAN, S. (2001) The varieties of grief experience. *Clinical Psychology Review,* 21, pp. 705

BOWLBY, J. (1969) *Attachment and Loss*. London: Pimlico

BOWLING, A. (1997) *Research Methods in Health: Investigating Health and Health Services.* 1st ed. Buckingham: Open University Press.

BRIDGING WORKING GROUP (2005) Bridging the gap between research and practice in bereavement: Report of the Centre for the Advancement of Health. *Death Studies,* 29, pp. 93-122

CENTRE FOR THE ADVANCEMENT OF HEALTH (2003) *Report on Bereavement and Grief Research.* Calgary: Open Society Insitiute of the Soras Foundation.

CHAPLIN, D. (2003) Clinical. A bereavement care service to address multicultural user needs. *Nursing Times,* 99(39), pp. 26-29

CHRIST, G., BONANNO, G., MALKINSON, R. and RUBIN, S. (2003) *Bereavement experiences after the death of a child.* In MARILYN J. FIELD and RICHARD E. BEHRMAN eds., *Institute of Medicine (2003) When children die: improving palliative and end of life care for children and their families.* Washington D.C.: The National Academies Press.

CLINICAL STANDARDS BOARD FOR SCOTLAND (2002) *Clinical standards: Specialist palliative care.* [online] Available from: http://www.nhshealthquality.org/nhsqis/files/SPC.pdf [Accessed 08/24 2006]

CORR, C.A., ATTIG, T., BOLUND, C., DEGNER, L.F., DE SPELDER, L., FOSTER, D.H., LEY, D.C.H., MORGAN, J.D., WASS, H., MORGAN, M.A., PACHOLSKI, R.A., QVARNSTROM, U., ROGERS, J., STEVENSON, R.G., WEBB, P. (The International Work Group on Death, Dying and Bereavement) (1991) A statement of assumptions and principles concerning education about death, dying and bereavement for professionals in health care and human services. *Omega*. 23(3), pp. 235-239.

DENZIN, N.K. and LINCOLN, Y.S., eds. (2003) *Strategies of qualitative enquiry.* 2nd ed. London: Sage.

DEPARTMENT OF HEALTH (2005) *When a patient dies: Advice on developing bereavement services in the NHS.* [online] Available from: http://www.dh.gov.uk/assetRoot/04/12/21/93/04122193.pdf [Accessed 08/25 2006]

FIELD, D., REID, D., PAYNE, S. and RELF, M. (2004) Survey of UK hospice and palliative care adult bereavement services. *International Journal of Palliative Care,* 10(12), pp. 576-596

FIELD, D., REID, D., PAYNE, S., and RELF, M. (2005) Adult Bereavement Support in Five Hospices in England. Palliative Care and End-of-Life Care Research Group, University of Sheffield.

FULTON, G., MADDEN, C. and MINICHIELLO, V. (1996) The social construction of anticipatory grief. *Social Science and Medicine,* 43(9), pp. 1349-1358

GENERAL REGISTER OFFICE FOR SCOTLAND (2004) *Vital events reference tables 2004.* [online] Available from: http://www.gro-scotland.gov.uk/files/04t5-2.pdf [Accessed 08/31 2006]

GREENSTREET, W. (2004) Why nurses need to understand the principles of bereavement theory. *British Journal of Nursing,* 13(10), pp 590-593

GUARDIAN UNLIMITED (2006) *Saying goodbye our way.* [online] Available from: http://www.guardian.co.uk/family/story/0,,1853044,00.html [Accessed 08/19 2006]

HEYSE-MOORE, L.H. (1996) On spiritual pain in the dying. *Mortality,* 1, pp. 297-315

HULL, A.M., ALEXANDER, D.A. and KLEIN, S. (2002) Survivors of the Piper Alpha oil platform disaster: long term follow up study. *British Journal of Psychiatry,* 181, pp. 433-438

JANSSEN, H.J. (1996) A critical review of pathological grief following pregnancy loss. *Omega,* 33, pp. 21-42

JOHNSON, K. (2004) Grief in North America, a death denying society. *International Journal of Palliative Nursing,* 10(9), pp. 435-435

JORDAN, R. and NEIMEYER, R.A. (2003) Does grief counselling work? *Death Studies,* 27, pp. 765-786

KASETENBAUM, R. (1992) *The Psychology of Death.* New York: Springer Publishing Co.

KENNEDY, I. (2001) *The report of the public enquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995.* [online] Available from: http://www.bristol-inquiry.org.uk/final_report/the_report.pdf [Accessed 08/24 2006]

KLASS, D., SILVERMAN, P.R. and NICKMAN, S. (1996) *Continuing Bonds: New Understandings of Grief.* Washington D.C.: Taylor Francis.

KUBLER-ROSS, E. (1995) *On Death and Dying*. 2nd ed., London, Routledge.

LEARNING AND TEACHING SCOTLAND (2006) *Health promoting schools: Family and community.* [online] Available from: http://www.healthpromotingschools.co.uk/familyandcommunity/emotional wellbeing/topics/bereavement.asp [Accessed 08/29 2006]

LINDEMANN, E. (1994) Symptomatology and management of acute grief. 1944. *The American Journal of Psychiatry,* 151(6 Suppl (Print)), pp. 155-160

LINDSTRØM, T.C. (2002) "It ain't necessarily so"...Challenging mainstream thinking about bereavement. *Family & community health,* 25(1), pp. 11-21

LLOYD-WILLIAMS, M. (1995) Bereavement referrals to a psychiatric service: an audit. *European Journal of Cancer Care,* 4(1), pp. 17-19

LOWTON, K. and PAYNE, S. (2004) Bereavement in the classroom. *European Journal of Palliative Care,* 11(1), pp. 28-31

MACGUIRE, J.M. (2006) Putting nursing research findings into practice: research utilization as an aspect of the management of change. *Journal of Advanced Nursing,* 53(1), pp. 65-71

MACMILLAN CANCER RELIEF (2001) *The Gold Standards Framework project in community palliative care (Phase 2).* London: Macmillan Cancer Relief.

MCLAREN, J. (1998) A new understanding of grief: a counsellor's perspective. *Mortality,* 3(3), pp. 275-290

MORSE, J.M., ed. (1989) *Qualitative Nursing Research.* Newbury Park: Sage.

NATIONAL HEALTH SERVICE (2006) *Don't give up giving up.* [online] Available from:
http://www.givingupsmoking.co.uk/CNI/Current_Campaign/new/
[Accessed 08/25 2006]

NHS EDUCATION FOR SCOTLAND (2006) *E-library.* [online] Available from: http://www.elib.scot.nhs.uk/portal/elib/pages/index.aspx [Accessed 08/31 1006]

NICE (2004) *Improving supportive and palliative care for adults with cancer.* London: NICE.

NIGHTINGALE, E., MOIR, S. and BARNES, T. (1998) *Principles of the Provision of Bereavement Support by Palliative Care Services in Australia.* Canberra: Commonwealth of Australia.

NOTRE DAME CENTRE (2006) *Seasons for Growth.* [online] Available from:
http://www.notredamecentre.org.uk/main.aspx?page=seasons&id=30
[Accessed 09/29 2006]

PARKES, C.M. (1972) *Bereavement: Studies of Grief in Adult Life.* London: Penguin.

PARKES, C.M. (2001) A historical overview of the scientific study of bereavement. In: M.S. STROBE, R.O. HANSSON, W. STROEBE and H. SCHUT, eds. *Handbook of Bereavement Research: Consequences. Coping and Care.* Washington: American Psychological Association.

PARKES, C.M., LAUGANI, P. and YOUNG, B. (1997) *Death and Bereavement Across Cultures.* London: Routledge.

PAYNE, S. and FIELD, D. (2004) Undertaking bereavement research: sensitivities and sensibilities. *Grief Matters,* 7(3), pp. 52-56

PAYNE, S., JARRETT, N., WILES, R. and FIELD, D. (2002) Counselling strategies for bereaved people offered in primary care. *Counselling Psychology Quarterly,* 15(2), pp. 161-177

QSR INTERNATIONAL (2006) *NVivo 7 is now available.* [online] Available from:
http://www.qsrinternational.com/products/productoverview/NVivo_7.htm
[Accessed 7/25 2006]

RAPHAEL, B., MINKOV, C. and DOBSON, H. (2001) Psychotherapeutic and Pharmacological Interventions in Bereaved Persons. In: M. STROEBE, R.O. HANSSON, W. STROEBE and H. SCHUT, eds. *Handbook of Bereavement Research: Consequences, Coping and Care.* Washington: American Psychological Association.

REDFERN, M., KEELING, J.W. and POWELL, E. (2001) *The Royal Liverpool Children's Inquiry: Report.* [online] Available from: http://www.rlcinquiry.org.uk/download/chap1.pdf#search=%22Alder%20Hey%20enquiry%22 [Accessed 08/24 2006]

RE-TELL LTD (2006) [online] Middlesex: Re-Tell. Available from: http://www.retellrecorders.co.uk/ [Accessed 09/01 2006]

RHODES (2001) Death and Dying. *Encyclopaedia of Life Sciences*.

RIBBENS-MCCARTHY, J. and JESSOP, J. (2005) *Young People, Bereavement and Loss.* London: National Children's Bureau.

RICHARDS, L. (2005) *Handling qualitative data: A practical guide.* London: Sage.

RICHARDSON, S. and PEARSON, M. (1995) Dignity and aspirations denied: unmet health and social care needs in an inner-city area. *Health & Social Care in the Community,* 3(5), pp. 279-287

ROSS, L. (1997) The nurses role in assessing and responding to patients' spiritual needs. *International Journal of Palliative Nursing,* 3, pp. 37-42

SANDLER, I.N., AYERS, T.S., WOLCHIK, S.A., TEIN, J., KWOK, O., HAINE, R.A., TWOHEY-JACOBS, J., SUTER, J., LIN, K., PADGETT-JONES, S., WEYER, J.L., COLE, E., KRIEGE, G. and GRIFFIN, W.A. (2003) The family bereavement program: efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. *Journal of Consulting and Clinical Psychology,* 71(3), pp. 587-600

SCHUT, H., STROEBE, M.S., VAN DEN BOUT, J. and TERHEGGEN, M. (2001) The Efficacy of Bereavement Interventions: Determining Who Benefits. In: M.S. STROEBE, R.O. HANSSON, W. STROEBE and H. SCHUT, eds. *Handbook of Bereavement Research: Consequences, Coping and Care.* 3rd ed. Washington: American Psychological Association.

SCOTTISH EXECUTIVE (2002) *Community Care and Health (Scotland) Act 2002.* Edinburgh, HMSO.

SCOTTISH EXECUTIVE (2005) *Happy, safe and achieving their potential: A standard of support for children and young people in Scottish schools. Executive summary.* [online] Available from:
http://www.scotland.gov.uk/Resource/Doc/36496/0023597.pdf [Accessed 08/29 2006]

SCOTTISH EXECUTIVE HEALTH DEPARTMENT(2005) *A National Framework for Service Change in the NHS in Scotland.* [online]
http://www.scotland.gov.uk/Resource/Doc/924/0012113.pdf [Accessed 08/29 2006]

SCOTTISH EXECUTIVE (2006) *See me: Lets stop the stigma of mental health.* [online] Available from: http://www.seemescotland.org.uk/ [Accessed 08/25 2006]

SERVATY-SEIB, H.L. and HAYSLIP, B. (2003) Post-loss adjustment and funeral perceptions of parentally bereaved adolescents and adults. *Omega,* 46, pp. 251-251

STREOBE, W., SCHUT, H. and STROEBE, M.S. (2005) Grief work, disclosure and counselling: do they help the bereaved? *Clinical Psychology Review,* 25, pp. 395-414

STROEBE, M.S., HANSSON, R.O., STROEBE, W. and SCHUT, H., eds. (2001) *Handbook of Bereavement Research: consequences, coping and care.* Washington: American Psychological Association

STROEBE, M. and SCHUT, H. (1999) The dual process model of coping with bereavement: rationale and description. *Death Studies,* 23, pp. 197-224

STROEBE, M., STROEBE, W. and SCHUT, H. (2003) Bereavement research: methodological issues and ethical concerns. *Palliative medicine,* 17(3), pp. 235-240

THE KING'S FUND (2006) *Pippa Gough.* [online] London: Torchbox.
Available from:
http://www.kingsfund.org.uk/about_us/whos_who/pippa_gough.html
Accessed 09/01 2006]

THE NUCLEUS GROUP (2004) *Review of Specific Grief and Bereavement Service.* [online]
http://www.health.vic.gov.au/palliativecare/finalrep_grief.pdf [Accessed 08/25 2006]

WASS H (2004). **"A perspective on the current state of death education."** *Death Studies* 28: 289-308.

WEST BJM, MACDUFF C, MCBAIN M and GASS J (2006) *An Evaluation of the Development and Implementation of the NHS Education for Scotland Cleanliness Champions Programme.* Robert Gordon University, Aberdeen.

WILES, R., JARRETT, N., PAYNE, S. and FIELD, D. (2002) Referrals for bereavement counselling in primary care: a qualitative study. *Patient Education & Counseling,* 48(1), pp. 79-85

WILLCOX, D. (1994) *Participation Guide*. Brighton: Partnership Books.

WIMPENNY, P., UNWIN, R., DEMPSTER, P., GRUNDY, M., WORK, F., BROWN, A. and WILCOCK, SE. (2006) *Literature Review on Bereavement and Bereavement Care.* [online] The Robert Gordon University. Available from: http://www.rgu.ac.uk/files/BereavementFinal.pdf [Accessed 06/27 2006]

WORDEN, J.W. (1991) *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner.* New York: Springer.

Appendix 1

Research Team and Steering Group Members

The Research Team

Alison Brown (AB), Lecturer, The Robert Gordon University (RGU)

Paul Dempster (PD), PhD student, RGU

Colin Macduff (CM), Lecturer, RGU

Fiona Ramage (FR) Secretarial/Administrative Support, RGU

Audrey Stephen (AS), Research Fellow Health Services Research, RGU

Rachel Unwin (RU), Lecturer, RGU

Sylvia Wilcock (SW), Director, Joanna Briggs Collaborating Centre, RGU

Peter Wimpenny (PW), Associate Director, Joanna Briggs Collaborating Centre, RGU

Fiona Work (FW), Lecturer, PhD student, RGU

Steering Group

Penny Bond, Professional Development Officer, NHS Quality Improvement Scotland

Fiona Dagge–Bell, Professional Practice Development Officer, NHS Quality Improvement Scotland

Theresa Fyffe, Deputy Chief Nursing Officer, Scottish Executive Health Department

Fiona Halcrow, Quality Manager, Scottish Executive Health Department

Liz Jamieson, Professional Officer, NHS Education for Scotland

Appendix 2

Letters (initial key contacts, snowball sample, additional contacts)

INTERVIEW INVITATION LETTER TO PREVIOUS Phase 1 CONTACTS

March 2006

Consultation and mapping of bereavement care practice in Scotland

Dear *insert name*

Thank you very much indeed for contributing to the literature review on bereavement and bereavement care that our team carried out during 2005. Please find enclosed a copy of the executive summary of the report. If you would like a copy of the full report, we would be very happy to provide you with one on request.

A further phase of the study has now been commissioned (Phase 2) with a view to producing an initial indicative mapping of current bereavement care practice against the evidence identified by the literature review. This mapping will form the basis for discussion at a facilitated workshop in June 2006 and will inform subsequent policy development in Scotland.

In this regard I am writing to invite you to take part in a short interview. This would ask you for some more details about the information that you kindly shared with us. It would also explore your perceptions of current bereavement care practice locally and nationally, and the match between these and the findings of the literature review (please see pages 2 and 3 of the executive summary). Finally you would be asked if there is any other person whom we should interview about bereavement care practices locally or nationally.

The interview would normally be undertaken by telephone and be recorded (with your permission). It would last between 20-30 minutes. The attached consent form invites you to indicate your preference in regard to being identified in the study report, or remaining anonymous. You would be free to withdraw from the study at any time without giving a reason.

I hope that my requests are not too onerous and that you are able to participate, as we want to be sure that we understand key issues about bereavement care practice to inform future policy and practice. I have attached a sheet with more information about the study, the consent form, and an appointment date and contact details form. Please complete the forms and return them to us by **date.** If you have any queries about the project, please contact me on 01224 262650 or e-mail p.wimpenny@rgu.ac.uk, or Audrey Stephen on 01224 262672 or e-mail a.i.stephen@rgu.ac.uk.

Yours sincerely

Dr Peter Wimpenny,

on behalf of..............*list team members*

INTERVIEW INVITATION LETTER TO "SNOWBALL" CONTACTS

April 2006

Consultation and mapping of bereavement care practice in Scotland

Dear *insert name*

I am writing to invite you to take part in a short interview exploring your perceptions of current bereavement care practice locally and nationally.

During 2005 our team from the Joanna Briggs Collaborating Centre here at the Robert Gordon University carried out a review of literature on bereavement and bereavement care commissioned by NHS Quality Improvement Scotland (NHSQIS), Scottish Executive Health Department (SEHD), and NHS Education for Scotland (NES). Please find enclosed a copy of the executive summary of the report for your information. A further phase of the study has recently been commissioned (Phase 2) with a view to producing an initial indicative mapping of current bereavement care practice against the evidence for good practice identified by the literature review. This mapping will form the basis for discussion at a facilitated workshop in June 2006 and will inform subsequent policy development in Scotland.

Interviews with initial key contacts in the NHS, the voluntary sector and other agencies/organisations have now taken place. During this process, you were identified as someone whom we should approach in order to obtain a more complete picture of bereavement care practice. The proposed interview would explore your perceptions of current bereavement care practice locally and nationally, and the match between these and the findings of the literature review (please see pages 2 and 3 of the executive summary). Finally you would be asked if there is any other person whom we should interview about bereavement care practices locally or nationally.

The interview would normally be undertaken by telephone and be recorded (with your permission). It would last between 20-30 minutes. The attached consent form also invites you to indicate your preference in regard to being identified in the study report, or remaining anonymous. You would be free to withdraw from the study at any time without giving a reason.

I hope that my requests are not too onerous and that you are able to participate, as we want to be sure that we understand key issues about bereavement care practice to inform future policy and practice. I have attached a sheet with more information about the study, a consent form, and an appointment date and contact form. Please complete the forms and return them to us by *date.* If you have any queries about the project, please contact me on 01224 262650 or e-mail p.wimpenny@rgu.ac.uk, or Audrey Stephen on 01224 262672 or e-mail a.i.stephen@rgu.ac.uk.

Yours sincerely, Dr Peter Wimpenny, on behalf of..............*list team members*

INTERVIEW INVITATION LETTER (All other contacts)

March 2006

Consultation and mapping of bereavement care practice in Scotland

Dear *insert name*

We are carrying out a consultation and mapping exercise of bereavement care practice in Scotland. We are interested in including the point of view of a representative of your organisation who is involved in the development of bereavement policy and practice. During 2005 our team from the Joanna Briggs Collaborating Centre here at the Robert Gordon University carried out a review of literature on bereavement and bereavement care commissioned by NHS Quality Improvement Scotland (NHSQIS), Scottish Executive Health Department (SEHD), and NHS Education for Scotland (NES). Please find enclosed a copy of the executive summary of the report for your information. This is the second phase of the project and builds on the literature review (Phase 1) that has already been completed.

This further phase of the study has now been commissioned (Phase 2) with a view to producing an initial indicative mapping of current bereavement care practice against the evidence identified by the literature review. This mapping will form the basis for discussion at a facilitated workshop in June 2006 and will inform subsequent policy development in Scotland.

In this regard I am writing to invite a member of your organisation to take part in a short interview. It would explore perceptions of current bereavement care practice locally and nationally, and the match between these and the findings of the literature review (please see pages 2 and 3 of the executive summary). Finally we will ask if there is any other person whom we should interview about bereavement care practices locally or nationally.

The interview would normally be undertaken by telephone and be recorded (with permission). It would last between 20-30 minutes. The attached

consent form invites participants to indicate preference in regard to being identified in the study report, or remaining anonymous. Participants would be free to withdraw from the study at any time without giving a reason.

I hope that my requests are not too onerous and that a representative of your organisation is able to participate, as we want to be sure that we understand key issues about bereavement care practice from the perspective of those closely involved. I have attached a sheet with more information about the study, a consent form, and an appointment date and contact form. Please complete the forms or pass them to a suitable representative, and return them to us by *date.* If you have any queries about the project, please contact me on 01224 262650 or e-mail p.wimpenny@rgu.ac.uk, or Audrey Stephen on 01224 262672 or e-mail a.i.stephen@rgu.ac.uk.

Yours sincerely, Dr Peter Wimpenny, on behalf of..............*list team members*

Appendix 3

Information Sheet

**CONSULTATION AND MAPPING OF BEREAVEMENT CARE PRACTICE:
INFORMATION SHEET**

This briefing sheet provides more information about the above study. Phase 1 of the study (2005) was a review of literature on bereavement and bereavement care. Please find a copy of the executive summary of the report attached for your information. As you will see, the study mapped key areas found in the literature and identified 13 key messages.

A further phase of the study has now been commissioned (Phase 2) in which we will consult with contacts established in Phase 1 and some new contacts. We will also be sharing the outcomes of both phases of the study with an invited audience to determine recommendations to be made relating to policy and practice.

The main data collection phase of the study will be taking place between March and May 2006. This will involve interviews (mostly by telephone) with a number of key contacts from the NHS, the voluntary sector, and other agencies/organisations who may or may not have contributed literature to the first phase of the study. The interviews will explore perceptions of local and national practice, and the match between these and the findings of the literature review. Perceived priorities for action will also be identified. These individuals will then be asked if there are any other persons whom we should interview in relation to establishing an indicative picture of bereavement care practice. In this way a second round of interviews will take place, using a similar format.

All interviews will be recorded with the consent of the interviewee who will be able to indicate their preference in regard to being identified in the study report, or remaining anonymous. The recording will be kept securely within the Faculty of Health and Social Care. Participants will be free to withdraw from the study at any time without giving a reason. The study has been deemed as service evaluation through NHS Research Ethics Committee consultation and has ethical approval from RGU.

The final report will be available in the autumn of 2006, and an executive summary will be sent to all interviewees. Should you require any further information about the study, or if you have any questions, please do not hesitate to contact us.

Dr Peter Wimpenny, Associate Director, Joanna Briggs Collaborating Centre, Robert Gordon University. Telephone 01224 262650. E-mail: p.wimpenny@rgu.ac.uk. Audrey Stephen, Research Fellow on 01224 262672 or e-mail a.i.stephen@rgu.ac.uk.

Rachel Unwin, Resarch Fellow on 01224 262672 or e-mail rachel.unwin2@nhs.net.

Appendix 4

Consent Form

CONSENT FORM

Title of Project: Consultation and mapping of bereavement care practice in Scotland

Name of Principal Researcher: Dr Peter Wimpenny, The Robert Gordon University, Aberdeen

I have read the letter of invitation to take part in the above study, and the associated information sheet. I understand that I am free to withdraw from the study at any time, without giving a reason. I have decided:

Please tick one box only

To take part on the basis that my name, employing organisation, and any relevant bereavement care information and interview data that I provide may be used in the study report.

To take part on the basis that all relevant bereavement care information and interview data that I provide are anonymised and/or aggregated in such a way that attribution to a specific individual and/or organisation is avoided in the study report

Not to take part in the study

Name (in capitals) ....

Signed...

Date.......................................

Address...

....

....

Thank you very much. Please return this form in the FREEPOST envelope provided.

Appendix 5

Advanced Organiser

APPOINTMENT TIMES AND CONTACT DETAILS FOR INTERVIEES

Consultation and mapping of bereavement care practice in Scotland

Thank you for agreeing to take part in a telephone interview as part of the above study. In order to arrange a mutually convenient time for the interview I would be grateful if you could indicate in the table below some suitable dates and times. We would like to complete your interview before **31st May**.

Name

_____

Organisation

_____

Date	Morning (please state a time)	Afternoon (please state a time)	Evening (please state a time)

I will contact you shortly to finalise a date and time. Please indicate the best telephone number for our phone interview:

Best   telephone   number

_____

Alternative   number

_____

Email   address

_____

Dr Peter Wimpenny, 01224 262650. E-mail: p.wimpenny@rgu.ac.uk
Audrey Stephen, 01224 262672 or e-mail a.i.stephen@rgu.ac.uk

_____

Thank you very much. Please return this form, along with the completed consent form, in the FREEPOST envelope

Appendix 6

Interview Schedule

<u>Interview Schedule for Phase 2 – Bereavement and Bereavement Care</u>

Date...

Time of interview **Start.**..

Interviewer..

Name – .	
Position -	
Role -	
Contact details -	
Type of Organisation	

Material sent..

1. Are you happy to undertake this telephone interview and have it recorded for use in our consultation and mapping exercise on bereavement care?   You (or will) have signed a consent form indicating that you were willing to either:

a) use you name and organisation or

b) for these to be anonymised.

(In relation to the following questions try to establish whether interviewee is talking primarily at the level of personal experience and opinion, or if they feel that they can provide a wider picture of organisational practice)

2. a) Can you tell me about your involvement in bereavement care?

b) Can you tell me about your organisation's involvement in bereavement care?

3.. Thinking of the information you provided can you tell me more about its development? *(e.g. why, when, where, how it was developed)*

**4. Can you describe how it is used in practice?**

5. What impact has your approach to bereavement care had in/on practice? (What works well? If anything, what might you like to change?)

6.. Do you think the approach to bereavement care that you have described could be used in other places or settings?

Now ask interviewee if they have read the Executive Summary and if so could focus on pages 2 & 3

7. Looking at the key areas from the literature review:

a) Which of these areas relate particularly to your work and that of your organisation? (*circle all that apply*)
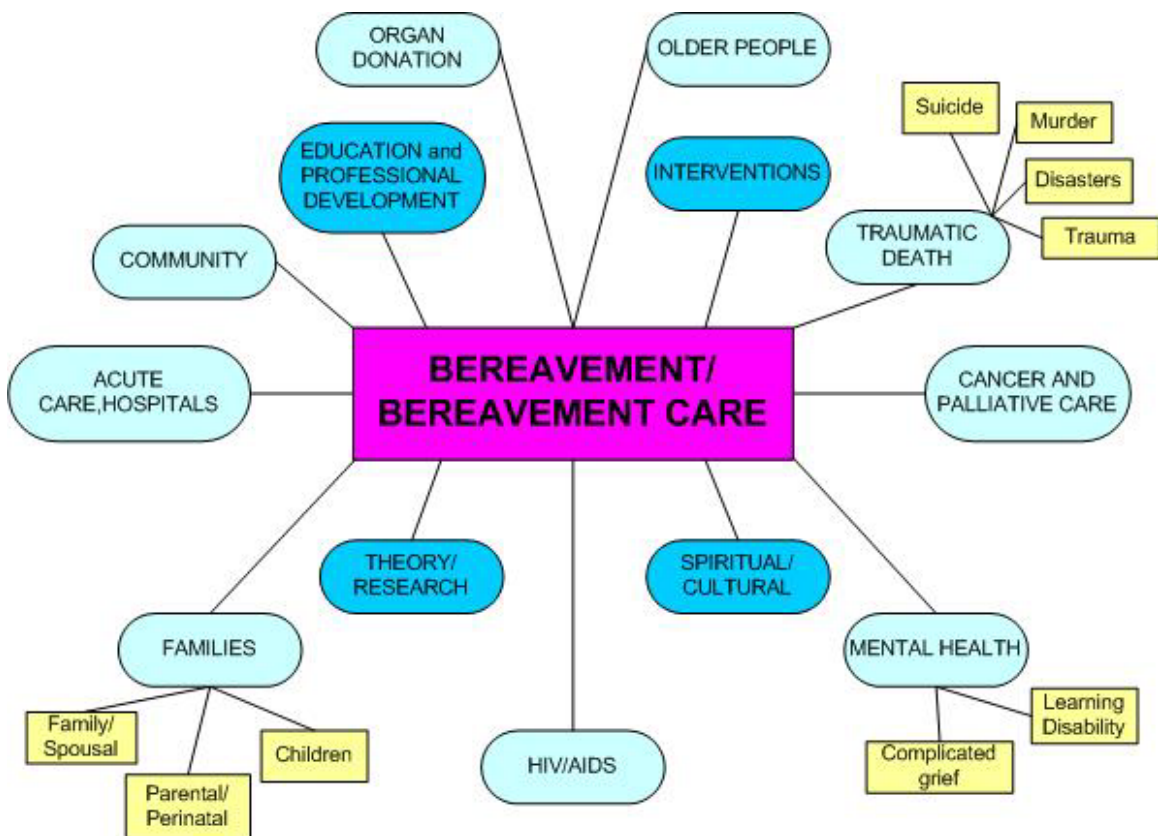
b)what do you see as the priorities for improving practice in bereavement care in these areas?

c)are there any important areas not covered in the literature review?

8) Looking at the 13 key messages from the literature review (page 2-3) are there any that you would see as a priority for your work and that of your organisation? *(if so, which? Maximum of three)*

Grief is a normal process.	
A compassionate approach to all procedures and processes surrounding death can impact positively on bereavement. The involvement of relatives and families is essential.	
Risk factors for abnormal responses are amenable to assessment.	
Interventions should be tailored to need. Specific groups of bereaved may require different forms of intervention.	
Follow-up has been identified as important, particularly by the bereaved.	
There are a range of information needs that need to be addressed at local and national levels.	
There are 'hidden' socio economic factors, particularly for some groups of bereaved that need to be considered.	
Cultural and spiritual factors, including issues of stigma need to be incorporated into all areas of bereavement care.	
A co-ordinated approach to bereavement and bereavement care that cuts across statutory and voluntary agencies is required.	
Standards, policies and guidelines for Bereavement Care should be considered in all settings	
Education for health and social care professionals is identified as in need of development.	
Research into bereavement and bereavement care is particularly difficult	

| but essential in developing services. | |
| Establishing a *Centre for Bereavement Care* may provide a focal point for developing research, education and practice in Scotland. | |

9. Thinking of the Scottish national context, where are the biggest gaps between the key messages and actual practice?

a) conversely where is there the closest match?

10) Do you have any other comments that you'd like to share in relation to policy, practice and the findings of the literature review? *(if so, what?)*

11) Check nature/level of attribution that interviewee is happy with re. reporting
(i.e. personal and organisational identification, or anonymised only)

12) Finally, is there anyone else whom you think we should interview in relation to bereavement care practice? *(name and contact details please)*

Finish time...

Appendix 7

Programme for Bereavement Care Workshop

Bereavement Care Workshop

Thursday 6th July 2006

Campanile Hotel, Tunnel Street, Glasgow

Aims

- To explore how the findings of the Bereavement Care Project to date may shape and influence policy and practice;
- To consider what actions may be necessary to address the challenges for change and improvements in care; and
- To meet and network with people from across the system with an interest in bereavement care.

09.30	Coffee and registration	
10.00	Welcome and introduction:	Paul Martin
		Chief Nursing Officer
10.10	Literature Review: Key Messages	Colin MurrayParkes
		Life President CRUSE
10. 25	Teasing out the challenges/ issues	Pippa Gough
		Kings Fund
11.45	Plenary session	
12.00	Exploring possibilities for change	
13.00	*Lunch*	
14.00	Plenary session and setting agenda for Open Space	

14.15   Briefing for Open Space:

14.40   Meetings convened: actions to address the challenges

              Tea as appropriate

15.40   Plenary session: headlines of actions

16.20   Closing remarks. What happens next.   Paul Martin

16.30   Close

Pippa Gough
12 June 2006