



LITERATURE REVIEW ON BEREAVEMENT AND BEREAVEMENT CARE



THE JOANNA BRIGGS INSTITUTE



Joanna Briggs Collaborating Centre for Evidence-based Multi-professional Practice

**FACULTY OF HEALTH AND SOCIAL CARE
THE ROBERT GORDON UNIVERSITY, ABERDEEN**

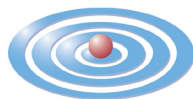
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In addition, many thanks go to those who emailed, posted or phoned with information or comment for the review. Whilst we have not always been able to incorporate all the information received, it has assisted always in shaping the review

Finally, thanks go to our advisory group members who contributed their time and expertise and assisted us in making sense of both our approach to the review and the material we included in this final report.

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SECTION ONE: Introduction to Review and Methods

This first section provides the basis for the literature review processes employed herein (Chapter 1). It then undertakes a brief introduction to the subject of bereavement (Chapter 2) in an attempt to provide the reader with some key definitions and a brief background to the topic. The next section (Chapter 3) moves more fully into the review by outlining the complications of grief that can occur to a small but significant group of those who are bereaved. Whilst all grief is distressing, it is this group who appear to be most at risk for ongoing distress and for whom risk factors may be discerned before or earlier in their grieving process.

Chapter 1: Introduction to Literature Review

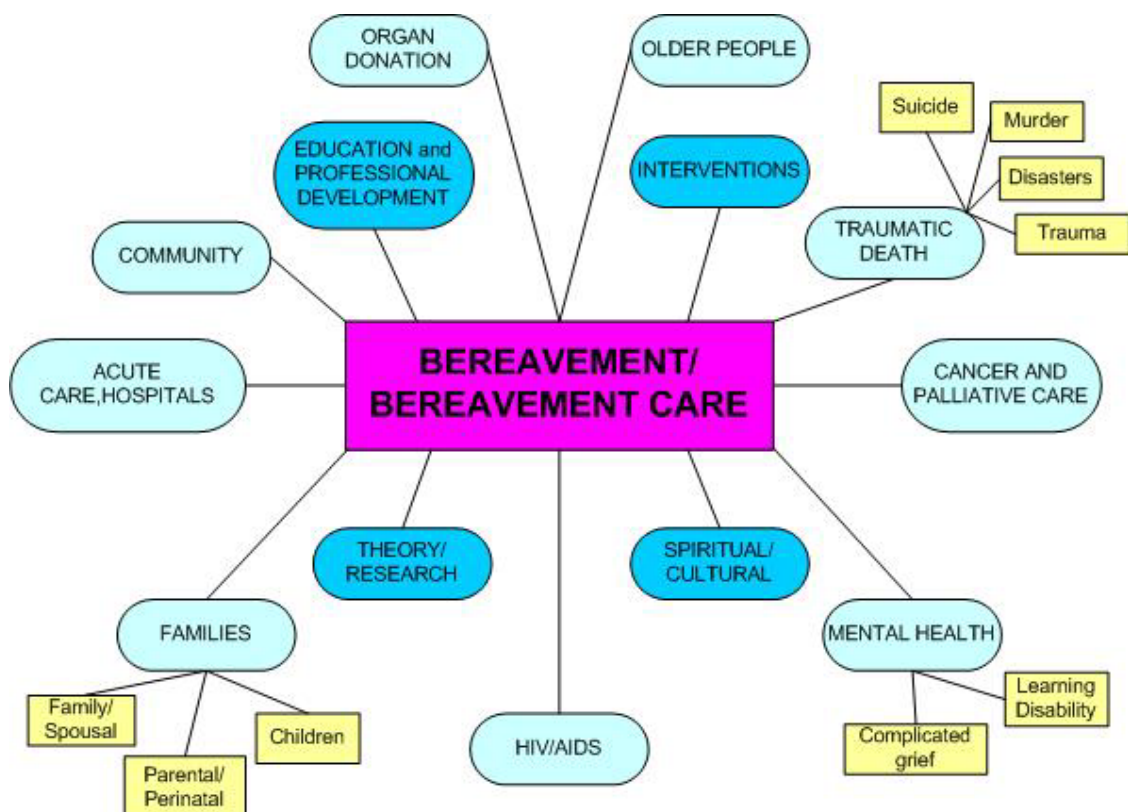
The purpose of this literature review was to inform Scottish Health and Social Care on the background, effects and outcome of bereavement and bereavement care. It was commissioned and funded by NHS Quality Improvement Scotland (QIS), Scottish Executive Health Department (SEHD) and NHS Education for Scotland (NES). The review has undertaken a wide sweep of bereavement literature in an attempt to illuminate the area and seek to identify key messages. From the outset the difficulties surrounding decisions about inclusions and exclusions of papers are acknowledged. Such decisions were made for a variety of factors. However, without such decisions the literature review, within the time available, was likely to flounder under the weight of evidence!

The review team has striven to attain a broad based review with appropriate appraisal of the reviewed evidence that may inform future policy and practice in Scotland. There was an explicit attempt not to focus just on issues of effectiveness as there would appear to be limited evidence and overall this would not assist in making decisions about the nature and provision of all aspects of bereavement care. For example, the outcomes from care at death are unlikely to be amenable to a randomised controlled trial or any form of controlled intervention, although there is evidence of the impact of such care from satisfaction surveys, qualitative research and opinion. Developing policy or practice to reflect such evidence would appear appropriate and conform to the concept of evidence-informed practice (Research in Practice organisation¹). However, the review has been able to take only limited account of what is currently happening in Scotland with the result that the literature may reflect what is already happening on the ground. If this is not the case then the review could provide a stimulus for discussion and change.

¹ www.rip.org.uk

The selection and appraisal of evidence was undertaken by at least two members of the review team. MB undertook the evidence search through the library service at The Robert Gordon University. RU, PW and PD reviewed the search and selected papers for review. The themes were developed by this core group (see Figure 1 below) as the literature was reviewed and selected for initial inclusion in the review. It became clear that the amount of evidence of effectiveness (i.e. RCT type evidence) was low and therefore it was decided to use the themes as an organising matrix with selection of appropriate papers across different forms of evidence. The result was a listing of 6265 papers (in addition to a bibliography supplied by one of our advisory group members) and a second stage of selection was undertaken to reduce the number to a manageable quantity so that a review process could be undertaken within the available time frame. Although such reduction is inevitably fraught with concerns, it is not unusual (Greenhalgh 2005). There is no doubt, with more time, that further refinement and selectivity could have been undertaken in some areas of this review. However, this may also have limited the breadth of the work.

Figure 1: Map of key areas identified from the literature review



Making decisions on breadth versus depth, is not simple and we have sought to satisfy something of both camps. An attempt to add a further quality dimension to the review was the engagement of an advisory group with members from systematic review bodies and experts in the field of bereavement (Appendix 4). We are grateful to them for their time, expertise and feedback at key points during the review. Any errors in the report are, of course, our own. Their initial perspective was that this was an enormous task, a perspective with hindsight we would not disagree. One of the other messages was that much of the material was at the bottom of the evidence tree and additionally there was significant material in books and older seminal papers that would not be included in the review. Papers were selected therefore, on the basis that they appeared to have most potential to address our questions; and key texts identified through reading were incorporated into the narrative summaries of each theme. The inclusion of material from the *Handbook of Bereavement Research* (Stroebe et al 2001c) is an obvious example. However, formal appraisal of such material was beyond the scope of the review.

The appraisal process was then undertaken by all review group members working in pairs focusing on selected theme material. Appropriate appraisal instruments were used from the Joanna Briggs Institute (JBI) suite of tools, amended as appropriate, and also drawing on those used by the Scottish Intercollegiate Guidelines Network (SIGN 50), (Appendix 1). A 1-4 rating scale, amended from that developed by the JBI² was used as a guide for appraisal (Appendix 2): '1' reflects high quality evidence with small risk of bias, confounding factors or doubts of trustworthiness, whilst '4' reflects evidence with a high risk of bias, confounding factors or doubts of trustworthiness. The rating scale is used alongside different forms of evidence that reflect feasibility, appropriateness, meaningfulness and effectiveness of any phenomenon of interest or intervention (see Appendix

² <http://www.joannabriggs.edu.au>

3). It is a reflection of the range and type of evidence in this field that the majority of evidence was rated as level 3 or 4. This is not to suggest that evidence rated at 4 is not significant in terms of policy making or clinical practice. It is merely a reflection of the type of evidence that exists; its importance has to be assessed in the light of other factors. There is a consistent message throughout the topic of bereavement that there is little homogeneity across research and additionally there are difficulties in constructing research due to the nature of the topic.

Following appraisal of theme material, a narrative for each theme was created with no reference to the level of evidence, albeit the accompanying 'technical' document contains such information. This form of evidence presentation is not unusual, particularly in the circumstances surrounding a broad review including both quantitative and qualitative evidence (Dixon-Woods 2005). It was considered important to present the literature in a form that allows the reader to gain a feel for the theme without making judgements about the level of evidence. Such judgements have become problematic for guideline bodies such as SIGN and NICE (National Institute of Clinical Excellence), as there is a tendency to focus on recommendations supported by level 1 evidence when these may not be the most important within that setting or context. There are moves at both national guideline bodies to diminish the link between levels of evidence and level of recommendation to prevent such, potentially inappropriate, judgements being made.

The creation of the narratives in each theme was geared firstly to appraisal and then the development of key messages. This was undertaken by two members of the team for each theme, which ensured that appropriate appraisal was being undertaken and also the accompanying narrative represented the data or evidence extracted. It is noted that these narratives may be overly descriptive in an attempt to report the evidence in an objective manner. However, we did not set out to describe each paper, as per Cochrane review format or as presented in reviews, such as that undertaken by the Centre for the Advancement of Health (2003) as this was

not the remit for the review and in addition we considered this as unhelpful to the potential readers of the final report.

Five questions were devised to assist in the appraisal and extraction process. These were:

1. What present knowledge and practices are identified as underpinning bereavement care?
2. In what ways are individuals and organisations involved in bereavement care?
3. What is the experience of bereavement?
4. What interventions are effective in bereavement care?
5. What are the outcomes of bereavement care?

These questions formed a broad frame of reference, in addition to the specific objectives for the review:

- explore published and grey literature including relevant evidence from the UK and other countries, and from a broad range of service organisations;
- determine priorities for health services within this politically sensitive and multifaceted topic;
- capture current knowledge, practice and public perception;
- underpin and inform development in policy and practice in this area.

The objectives and questions provided a guide to the type of literature to be reviewed, however, the breadth indicated by these resulted in considerable discussion on both inclusion and exclusion criteria. As the review was anticipated to update the perspectives offered by *Everybody's Death should Matter to Somebody* (1991) a cut off date of 1990 was used. Earlier reference is included, but not reviewed, where the reviewers considered that it had relevance for the review.

Search Terms

The review team also found the definition of boundaries for bereavement and bereavement care difficult to identify. To maintain an open approach, the search terms used were broad:

Bereavement care as a phrase;

*Bereave** and *care*

grief and *loss*

death and *dying*

*mourn**

end of life

funeral and *funeral rights*

In addition *attitude* was added to each of these key words/phrases in an attempt to capture the public perception.

Databases

The breadth of material identified allowed the team to assess and discuss inclusion/exclusion for papers based on the likelihood of the paper assisting with answers to the above questions and objectives. The result was an initial large range of material (6265 papers), accessed from the following databases:

Ageline

AMED

ASSIA

CINAHL

EMBASE

ERIC

MEDLINE

PASCAL

PASCAL2

PSYCHINFO

SOCIAL WORK REVIEWS.

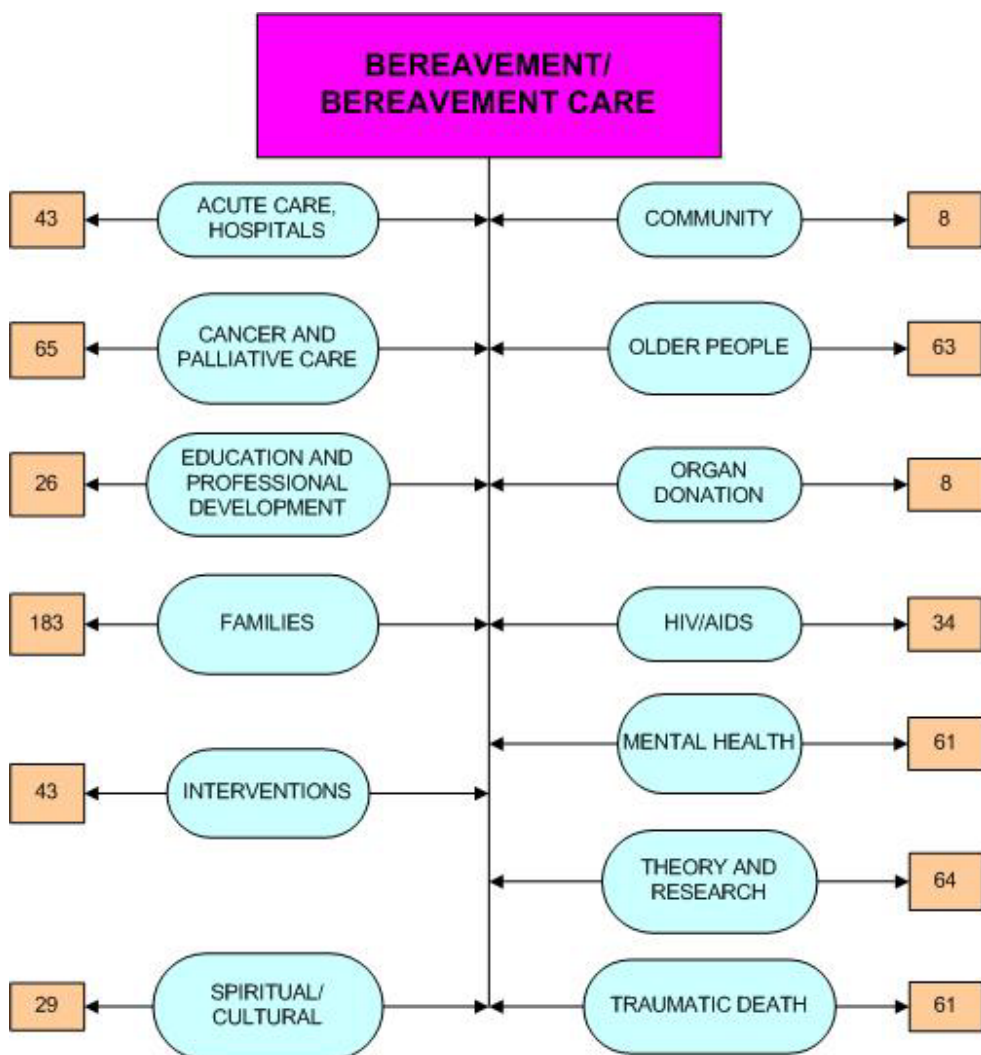
A first review of the papers through titles and abstracts then occurred, which resulted in 1888 papers being identified across the databases (see Table 1). Literature related to end of life care was difficult to assess for relevance as much of it related to dealing with death itself, as opposed to the bereaved, although clearly some of this would be related to impact, few papers were selected at initial review.

Table 1: Results of Primary Database Search

Database	Initial Number of Papers	Papers Selected on First Search
AGELINE	40	18
AMED	1261	561
ASSIA	899	199
CINAHL	717	119
EMBASE	752	468
ERIC	867	207
MEDLINE	795	161
PASCAL	28	25
PASCAL 2	137	50
PSYCHINFO	645	19
SOCIAL WORK REVIEWS	124	61
Total	6265	1888

From the 1888 papers the number was further reduced to 1408, with 687 full text copies being obtained through local libraries, electronic journals and interlibrary loans (235). The breakdown of these papers into themes, with the number of papers in each theme, is shown in Figure 2.

Figure 2. Number of papers identified with each theme at commencement of appraisal process



Exclusion occurred as papers were identified as duplicate or parallel publications; did not contribute to providing a perspective on the set objectives/questions; poor quality on appraisal; unable to access publication within the time scale or published before 1990.

Final identification of papers occurred through an ongoing discussion between at least two members of the review team (RU, PD or PW), and subsequent refining occurred with all members of the review team and comments from the advisory group. Amendments occurred to the themes as the review progressed.

Managing this significant number of references was undertaken using RefWorks™ and EndNote™ (Version 8). Without such reference management systems the process for large reviews, such as this would be logistically difficult.

In addition a call for other 'grey' materials was undertaken through a variety of different routes – letters to all Health Boards, Universities and Voluntary groups; emails to networks such as CHAIN (Contact, Help, Advice and Information Network) and JBI collaborating centres. A review of the informational type of literature was undertaken by PD and a separate synopsis of this has been developed (see Chapter 13). We also received a number of telephone calls and emails from a variety of individuals and organisations for which we are grateful as it assisted us to develop the thematic matrix. Other materials, such as policy documents, were incorporated into the narratives wherever possible.

A database was developed using Microsoft Access™, to hold the appraisals and extractions from systematic/literature reviews and quantitative papers. The qualitative and text/opinion papers were appraised and data extracted.

A final aspect of the review was a meeting held with representatives of the Scottish Executive Health Department to discuss the draft findings. A presentation by the review team was followed by discussion and feedback which we sought, wherever possible, to incorporate in the review. For completeness a brief note of the meeting and the issues raised are included in Appendix 5.

One final aspect that we would also wish to report in this opening section is the schism between objectivity and subjectivity. On the whole our review process kept bereavement at a distance, the focus was on appraising and

extracting data from papers, it was an objective exercise. However, our engagement with some of the personal (subjective) material often touched us emotionally. We witnessed the impact at the individual level and whilst it is hard to fit to any particular level of evidence evokes strong feelings. If it can do this to a set of 'objective' minded reviewers we believe that the impact of death and the subsequent bereavement is very powerful and as such demands significant attention in the fields of health and social care particularly, but also in others such as education. The inevitability of death and the power of its impact are without doubt real, the extent and manner which our society deals with this appears to be changing. The ability of this review to effect changes at such a level is not possible. However, it is hoped that it will raise the profile of bereavement and identify key messages from the literature that may inform future policy and practice.

An attempt to organise the material appraised and included in the review in a pathway format has been undertaken, from: grief and its complications in Section 1, through a review of bereavement across the lifespan (Section 2). Then an examination of specific but significant areas of bereavement in Section 3 followed by a closer inspection of particular health and social care settings (Section 4), has been undertaken. The final section (Section 5) highlights the issues surrounding research that were in evidence from the review of literature and maps out the overall key messages before reaching conclusions.

Chapter 2: Background to Bereavement for the Review

The literature appraised for this review covers a considerable range of perspectives, not all may be directly applicable to policy and practice. The evidence reviewed ranges from aspects of care that are practical and personal in orientation to that which raises concerns of a broader philosophical nature. Seeking to cover this range is fraught with dangers as there is a potential to 'get stuck in the swamp'. There are, it is conceded, specific aspects of practice that require further focused enquiry so that appropriate guidance can be formulated.

This background section is, briefly, to set the scene for bereavement care in general prior to the review sections. In general the review team was struck by the range of literature related to bereavement and bereavement care and also struggled to deal with the ambiguity and distinctions surrounding terminology (Stroebe et al 2001c). Furthermore the range of disciplines and professionals engaged in writing and researching on bereavement is such that there are, of course, issues of differing language and perspective (this range is reflected in the journals accessed).

Definitions

Often the language of death, dying, grief and the discourses of bereavement mean that terms are used interchangeably (Stroebe et al 2001c) and differ between organisations and agencies (London Bereavement Network 2001) and are therefore difficult to define. Throughout this review we used the broad definition of **bereavement** as 'the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one' (Christ et al 2003 p554), to guide us. It therefore followed that bereavement care may be defined as any care provided formally/informally through voluntary/health and social care

organisations in anticipation of or adjustment to living following bereavement.

Other definitions are equally problematic and broad in scope, as terms are used in a variety of ways throughout the bereavement literature. For example in respect of **counselling** it is acknowledged that within the bereavement field the term may refer to any engagement with the bereaved, irrespective of what it is called, particularly when so many voluntary agencies are involved (Bondi 2003). Unfortunately, differentiation is often not made in the literature and we have, wherever possible, sought to distinguish counselling from other forms such as a counselling approach or counselling skills and if carried out by professionals or volunteers, however, it is the case that we accept a lack of clarity in this area.

Other terms are perhaps less contentious: **grief** is defined as 'a primarily emotional (affective) reaction to the loss of a loved one through death' (Stroebe et al 2001 p6). It can have psychological and physical manifestations. **Mourning** is 'the social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group' (Stroebe et al 2001 p6). Terms related to 'abnormal' grief are addressed more fully in Chapter 3

Bereavement

The classic work of Lindemann (1944) 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 (for example Kubler-Ross). 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, Silverman and Nickman 1996) and a continual move between loss and restoration (Stroebe and Schut 2001). There is also evidence of social and medical models impacting upon the evidence.

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). In all cases there are probably policy and training implications (Kastenbaum 1992, Ross 1997). Examining the literature on bereavement and bereavement care and potential impacts on policy and practice, highlights the physical, psychological, sociological and spiritual, cultural and economic elements which are required to ensure an holistic view. However, the review undertaken would suggest that a considerable amount of evidence is found, perhaps rightly so, in the psychological and sociological literature with lesser amounts in the other elements.

Bonnano and Kaltman (2001), in a review of grief and bereavement, identify 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 from the outset that the majority of the bereaved, 90-95%, will 'recover' from their loss within a 'reasonable' time period (Centre for Advancement of Health 2003, Schut et al 2001). The definitions of 'recover' (Balk 2004) and 'reasonable' is difficult to specify as it will vary from individual to individual, although some broad time periods have been identified. It may also be the case for some, that recovery actually goes beyond pre loss levels of functioning (Lindstrom 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. It is to these outcomes that many of the papers reviewed refer, or investigate.

The time 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.

What is also apparent, as Parkes and others have described, is that there are factors which may impact on the outcomes and some of these 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 assessing 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 et al 1996).

There is of course a question of the need for intervention at all if grief is a 'normal' process from which most people will emerge (Raphael, Minkov and Dobson 2001). In addition the evidence of the effectiveness of interventions, is relatively weak (Jordan and Neimeyer 2003). However, there would appear to be many 'interventions' that do not fall within the clinical or medical use of the term that are applicable in this review, for example; 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, role of volunteers and voluntary groups etc. The effectiveness of many of these 'interventions' is difficult to ascertain but there is no doubt, from the literature that they have an impact and are part of the overall picture of death, dying and bereavement.

The range of clinical 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, Minkov and Dobson 2001). If intervention for bereavement is required then an integrative approach appears to be favoured, that is pharmacotherapy, psychotherapy and education provided by a range of agencies.

The following sections seek to illuminate the issues surrounding bereavement and bereavement care being raised in this background section. Because of the nature of death, dying and bereavement there will of course be overlap between the areas identified and covered. However, it is contended that this gives added strength to the overall key messages stated in Chapter 19.

Chapter 3: Complicated Grief

For the 5-10% of people who do not adapt 'normally' to their loss the grief process can become problematic, resulting in a reduced quality of life. Whilst many terms were used to describe this, there is a perspective emerging in the literature that this should be identified as complicated grief or traumatic grief. We have chosen to use, wherever possible, the term complicated grief to avoid confusion with grief associated with trauma.

The majority of materials in this section are observational studies or opinion pieces (evidence ratings are predominantly in the 3-4 level) that seek to establish distinctions between complicated grief and other diagnoses. Presently, it would appear that, there is no accepted diagnosis of complicated grief unless it is related to other mental health diagnoses. Therefore, those who are bereaved with signs and symptoms of complicated grief are often diagnosed with anxiety and depression or Post Traumatic Stress Disorder (PTSD), which may, or may not, be appropriate.

A review by the Centre for Advancement of Health (2003) illustrates that complicated grief is a potentially distinct clinical entity with decreased mental health, well being and functioning in life roles. The terms 'complicated grief' and 'traumatic grief' (Jacobs and Prigerson 2000, Prigerson and Jacobs 2001a) appear to be becoming more widely used to cover a range of terms and grief reactions, such as pathological, unresolved, exaggerated, masked, abnormal, morbid, delayed, chronic or absent grief (Middleton et al 1997, Worden 1991). The extent to which practitioners can distinguish between some of these is questionable (Enright and Marwit 2002). Identification of atypical grief reactions have been attributed to Parkes (1965) and often linked with anxiety and depressive symptomatology (Bonanno and Kaltman 2001), although they are considered to have distinctive features that are unique to bereavement irrespective of other mental health pathology (Centre for Advancement of Health 2003, Prigerson et al 1996).

It is suggested that the distinctive features of complicated/traumatic grief can be identified, with Prigerson et al (1995) indicating that the use of a specific scale for Complicated Grief (Inventory of Complicated Grief) or Traumatic Grief (Inventory of Traumatic Grief) (Prigerson and Jacobs 2001a, Boelen 2003a) can be potentially discriminatory and helpful in assessment. Hogan et al (2004) consider these still to be in need of further verification. Marwit (1996) indicates that diagnosis of complicated/traumatic grief is often interlinked with mental health diagnosis, particularly if using DSM classifications, whereas there are distinctive features of complicated or traumatic grief that are not incorporated into such classification.

Whilst complicated or traumatic grief is often linked with depression and anxiety, there are some key differences related to the ongoing relationship with the deceased, which, according to Prigerson et al (1996) need to be identified, although Bonnano and Kaltman (2001) indicate that the present diagnostic categories within DSM-IV can accommodate such atypical grief reactions. The common variables for complicated grief seem to be that the intensity of the grief reaction is either too much or too little and the duration is too long or too brief, in conjunction with other risk factors such as nature of the loss, cultural expectations, involvement of personality factors and unresolved earlier losses (Marwitt 1996).

The number of people identified as having complicated/traumatic grief from bereavement varies and has been estimated at about 15-20% of those who are bereaved (Prigerson and Jacobs 2001a, Bonnano and Kaltman 2001), although some reports indicate between 4-33% (Marwit 1995, Middleton et al 1996). It has also been estimated that about 33% of those using outpatient mental health services may also have some degree of complicated bereavement which is impacting on their present condition (Piper et al 2001).

Middleton (1997) indicated that, on average, symptoms of psychological distress associated with bereavement reduce over time (1 year in this study). However, for those with complicated grief, symptoms these may go beyond 18 months and be discernible at 6 months (Ott 2003). Additionally, Latham

and Prigerson (2004) identify an increased risk of suicide in those with complicated grief, which may increase, in ratio terms, over time. In addition to death by suicide it has been acknowledged that the bereaved are generally at higher risk of dying than non-bereaved (Stroebe et al 2001c), irrespective of type of bereavement but particularly for the younger bereaved; occurring during the early months after the loss. They may also, potentially, have a general lower quality of life in some areas of functioning (Silverman et al 2000).

Perceived social support and life stressors may play a role in complicated grief (Ott 2003). Barry et al (2002) indicate that the preparedness for death may also impact on its development. Ellifritt et al (2003), from a hospice-based bereavement service perspective, indicate that in addition to social support, history of drug and alcohol abuse, poor coping skills, history of mental illness, child death and concurrent crisis are all significant factors. In addition, Boelen et al (2003b) identify that negative perceptions of grief reactions by the bereaved can impact on distress and discomfort and contribute to traumatic grief and depression. Such views are echoed in the Scott and White Grief study (Gamino and Sewell 2004) where high risk factors help identify those with higher measured distress levels and where those expressing positive themes of hope and recovery fared better than those expressing themes of pain and suffering.

Jacobs and Prigerson (2000) indicate that a range of different psychotherapies (CBT, crisis intervention; brief dynamic psychotherapy; behaviour therapies; group therapy; other interpersonal psychotherapy group, individual therapy) have shown some evidence of effectiveness and may be appropriate but should be tailored to meet the individual's needs, particularly those identified as at high risk. They also identify the contribution of self-help groups in their review (as do Zisook and Shuchter in 2001, with the older work of Vachon et al in 1980 identified as significant) and indicate that studies suggest that such groups can be just as effective if the group has: leadership; has been screened for suitability and training for interventions has occurred. It is also estimated that 80% of bereavement

care is now provided by the voluntary sector (London Bereavement Network 2001) and therefore, it appears appropriate to propose that the quality of such care is strengthened. A broader review by the Centre for Reviews and Dissemination (Baker 1997) reported limited effect of bereavement counselling, although again highlights the widow-to-widow programme (Vachon et al 1980) as effective and in addition the potential benefits of programmes for children.

Cognitive behavioural therapy (CBT), in the present health care environment (managed health care and push for 'brief' psychotherapy), is viewed as ideal for treating individuals with complicated grief (Matthews and Marwit 2004). However, this is not necessarily supported by those who work in bereavement care and it is acknowledged that a need for further empirical support exists in this context and the possibility of using it in conjunction with other interventions. It is acknowledged that CBT, in general, has been shown to be effective in treating anxiety (including PTSD) and mood disorders.

Piper et al (2001), identify benefits from time-limited, short-term group therapy, particularly from an interpretative perspective and in patients assessed with specific personality traits. In a follow up of the same patients, social support appears to improve after therapy (Ogrodniczuk et al 2003).

There is a strong association between complicated and traumatic grief and anxiety and depression and it is considered a key factor in atypical grief reactions. Bonnano and Kaltman (2001) identify that all forms of depression and anxiety reduce over time in the bereaved although may be resistant to time in about 15% of widows and widowers. The DSM-IV (APA-IV 1994) convention is to wait for 2 months after the death before diagnosis of depression is made, although Zisook and Shuchter (2001) contest this time period as illogical and believe it delays appropriate diagnosis. In a review of the evidence for treatment of depression during bereavement they conclude that better assessment and adaptation of interventions should occur to identify and support those at risk more accurately (this could also include

prophylactic treatments). Treatment should consist of a combination of education, psychotherapy and pharmacotherapy. Reynolds et al (1999) (cited in Zisook and Shuchter 2001) identified the combination of medication (nortriptyline) and psychotherapy as associated with the highest rate of treatment completions. The type and duration of treatment would appear to be best based on individual requirements. A recent RCT (Shear 2005) highlights some benefit for complicated grief treatment over standard interpersonal psychotherapy, although both interventions show improvement.

Prescribing of anxiolytics, for those who are bereaved, has been considered inappropriate (BNF 2005) although no evidence appears to exist of detrimental effect. Warner and Metcalfe (2001) found no evidence of a positive or negative effect of benzodiazepines on the course of bereavement within the first 6 months after death.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter

Type of Evidence	Papers	Total
Complicated Grief		
Systematic or systematic type review	Baker et al (1997), Centre for the Advancement of Health (2003)	2
Literature or literature type review	Jacobs and Prigerson (2000)	1
Experimental/RCT	Piper et al (2001), Shear et al (2005), Warner and Metcalfe (2001)	3
Case Control and Cohort	Ogrodniczuk et al (2003)	1
Observational (no comparison group)	Barry et al (2002), Boelen et al (2003a), Boelen et al (2003b), Ellifritt et al (2003), Gamino and Sewell (2004), Hogan et al (2004), Latham and Prigerson (2004), Marwitt (1996), Middleton et al (1997), Ott (2003), Prigerson et al (1995), Prigerson et al (1996), Silverman et al (2000)	13
Mixed methods	Enwright and Marwit (2002)	1
Qualitative		
Opinion/text	Bonnano and Kaltman (2001), Matthews and Marwit (2004), Zisook and Schucter (2001)	3
Books/Book Chapters etc	BNF (2005), London Bereavement Network (2001), Stroebe et al (2001), Prigerson and Jacobs (2001), Worden (1991)	5
Pre 1990 reference	Parkes (1965), Vachon (1980)	2
TOTAL		31

Key messages in Complicated Grief

Assessment for the potential of complicated/traumatic grief (and depression) may be helpful in identifying at risk individuals. In addition, assessment at an appropriate period after death may help to establish the presence of complicated/traumatic grief.

Complicated/traumatic grief should be considered, often in conjunction with depression and anxiety, in those whose grief is short/prolonged or intensity is high/low.

Interventions for complicated grief are of uncertain effectiveness and have not been subjected to robust evaluation. They should be tailored to individual need and any accompanying depression or anxiety treated appropriately.

The contribution of self-help groups may be as effective as other interventions and could play a role in overall support for the bereaved.

A specific systematic review and development of guidance/best practice for the assessment and management of bereavement related depression and anxiety should be undertaken.

SECTION TWO: Bereavement across the Lifespan

This section covers evidence that is related to bereavement throughout the lifespan. It commences with bereavement in children (Chapter 4) which combines related evidence in areas of adolescent bereavement, sibling bereavement, children dying in hospital and organ and tissue donation. It also seeks to raise the issue of bereavement in education settings, where it may be argued considerable impact and influence are apparent for children. Chapter 5 moves to examine bereavement in the context of the parent who loses a child, irrespective of age, with Chapter 6 moving this into the family context including evidence related to spousal loss. Spousal loss is further examined in Chapter 6 when evidence related to older people and bereavement is examined. This is an area where a considerable amount of evidence has naturally been accrued and issues related to gender are of particular significance. Gender, as an issue related to bereavement, surfaces throughout this section and highlights significant differences in grief, mourning and outcomes for males and females. The final chapter in this section is a synopsis of evidence related to spiritual and cultural aspects of bereavement. It was considered appropriate to include this chapter within the section as there are obvious interconnections between death and bereavement across the lifespan and associated spiritual/cultural factors that influence this process.

Chapter 4: Childhood Bereavement

This synopsis of literature related to childhood bereavement is built around a small number of reviews of literature. Whilst none conform fully to the systematic review process, they cover considerable ground in this area and highlight some important key messages. Papers identified and included in these reviews were, on the whole, excluded from our review. The newest review by Ribbens McCarthy and Jessop (2005) is not strong in terms of effectiveness but is much stronger in terms of the applicability and meaningfulness aspects. The same is true of Lowton and Higginson's (2002) review whilst Curtis and Newman (2001) seek to establish effectiveness of community based interventions. All the reviews highlight the difficulties and paucity of 'good quality' research, this is reflected further in the Centre for Advancement of Health (2003) review, which actually selected no empirical studies related to childhood bereavement.

An extensive statement from the Work Group on Palliative Care for Children of the International Work Group on Death, Dying and Bereavement (Corr 1999) recognises that: all children grieve, although this may be in a different way to adults and may not be understood; children should, wherever possible, be included in experiences related to death and participate in the rituals and commemorations after a death; schools should have a role to play in supporting children who have been bereaved and also in the provision of education about death, dying and bereavement.

Ribbens McCarthy and Jessop (2005) set out to review 'relevant' literature on five questions related to *young people's experiences, behavioural outcomes, the responsiveness of agencies, theoretical assumptions and research methodology factors*. They acknowledge at the outset the extent and challenge of reviewing literature in this area and that the research evidence is 'fraught with contradictions' (p5). It is contended that the experience of bereavement for young people is not uncommon: it is estimated that about 2–6% of under 18 year olds have lost a parent or significant member of their

family (Lloyd-Williams 1998, CRUSE 1989, cited in Holland 2003, Harrison and Harrington 2001) and as such needs to be more widely acknowledged.

The case studies and qualitative research review presented by Ribbens McCarthy and Jessop (2005), highlights how significant bereavement is in young people's lives and how it can affect them well into the future. Social relationships, including increasing risk and vulnerability caused by the death of a parent and social isolation, coupled with lack of opportunity to talk are major themes from the voices of young people. Black (1996) clearly indicates that bereaved children benefit from involvement and discussion and not exclusion and denial. These themes are echoed in the available research where there is evidence of short and long term consequences, particularly when personal, social and material resources are low and other stressors are high. Approximately 17% of bereaved children will show significant behavioural problems beyond about four months after the death (Silverman and Worden 1992).

Lowton and Higginson (2002) identify this multi-factorial nature of pre-existing, current and subsequent factors on bereavement in children. Some evidence exists that boys are more affected in the short (Kalter 2002) and long term (depression in widowers) although this may be influenced by the response of the remaining parent or parents in the case of sibling loss. This finding is also reported by Sandler et al (2003) and highlights the potential that boys may differ from girls in regard to the types of, and timings for, support. The type of death does not seem to be significant, although those who lose fathers seem to do better (Black 1998). This may be due to mothers providing ease of communication to express grief and emotional care. Furthermore the social circumstances and context can increase difficulties, particularly related to material resources and the lack of local family support.

Ribbens McCarthy and Jessop (2005) indicate that the result of bereavement in childhood, particularly with the loss of a parent (significantly more so if a mother) may affect educational and employment achievements, result in

leaving home early, early sexual and partnering activities, criminal or disruptive behaviours, depression in the short and long term and diminution of self-concept and self-esteem. Kalter (2002) found limited evidence of such problems in the short term but that problems may occur in the longer term (>2years after death), a finding consistent with Silverman and Worden's (1992) work and reported as >1year by Black (1996/1998) when related to mental health disorders, particularly depression. Such delayed reactions may be due to the influence of bereavement on child care problems resulting from the death of a parent.

Assessment of the degree of cognitive, behavioural and emotional responses must take into account the complex interactions between the factors discussed above. Although some particular tools have been developed, they have been criticised for lack of sensitivity in children and being culturally bound. Using proxy respondents, such as a parent, can also be problematic as responses may be influenced by their own grief. However, in undertaking assessment there is a real problem in that no consensus exists as to who should be assessed – all children who experience bereavement or only those who show emotional/behavioural problems? Bunce and Rickards (2004) use an emotional resilience guide which may be useful in this context. They use it as part of a comprehensive guide for dealing with bereavement in children and highlight the necessary requisites for bereavement support.

The support available for young people who are bereaved is also considered problematic and largely unknown in terms of appropriateness and effectiveness. Nevertheless, what there is appears to be limited in co-ordination and integration across a range of sectors including education, health, youth services and the voluntary sector. In addition those most likely to need such services, particularly young people in areas of deprivation and disadvantage, are the least likely to have provision, access or referral.

Williams et al (1998) evaluated childhood bereavement groups which had the majority of children from deprived settings and contended that there was 'clear evidence' of social, behavioural and emotional improvement for most

children through the use of group work approaches. Sandler et al (2003) also demonstrate improvement, particularly for those most at risk, by using a structured Family Bereavement Programme, although it is not clear if such a structured programme could transfer to 'everyday' practice. Brown (2004) from a very different perspective outlines a remembrance day programme run by the voluntary sector. This illustrates how a range of formal and informal approaches to assisting children to deal with bereavement can be helpful and useful for developing social networks.

However, a review of bereavement programmes by Scheiderman et al (1994) concludes that there is no evidence of effectiveness and that it is likely that risk factors associated with class, pre-death family functioning, social support, age of the deceased and survivors and nature of death will be influential. Additionally, a later review by Curtis and Newman (2001) of community based interventions (outwith clinical settings) concludes that the inclusion of all bereaved children in support programmes remains unproven. Again they also advocate selective inclusion based on the type of known risk factors identified above.

Support programmes may have to be developed to deal with the aftermath of disasters, such as Dunblane, when the important factor is for provision of interventions to be carefully planned to prevent overprovision (Black 1996). A framework for bereavement 'services' and interventions for children is suggested by Melvin and Lukeman (2000) which charts a flexible chronological based approach. Lloyd-Williams (1998) highlights the potential for primary care to achieve better services for bereaved children by ensuring that recording is accurate, all primary care staff have involvement and that there is the potential for a family appointment 8-12 weeks after death to assess coping. However, Lowton and Higginson (2002), highlight the gaps in provision in primary care and the mismatch between need and service provision. They draw on the UK research of Thompson and Payne (2000) who identified that children have a range of questions about death and dying that are related to factual, social and emotional information. Providing

appropriate responses to such questions, irrespective of setting, seems imperative as other sources of information are often not available.

Corr (2004) identifies a range of death related literature that he considers useful to be read with or by children. His contention is that such literature can assist in raising and answering some of these crucial questions. Schuurman (2004) describes a range of selected literature for professionals and parents to assist them in supporting bereaved children. Both papers indicate the considerable range of literature available in this field for practitioners, parents and children to use individually or as part of a programme, intervention or by an individual.

Websites, such as *Cruse*³ and *Winston's Wish*⁴ are considered available but not widely known and limited in providing peer support. Provision of school based information and education for children is strongly endorsed, particularly as relevant curriculum materials are available. However, it would appear that many teachers may feel ill-equipped to handle this subject matter in the classroom. The Childhood Bereavement Network (CBN) provides a range of materials including guidelines for best practice by agencies offering bereavement support. The network seeks to develop a co-ordinated and collaborative approach to ensure quality information, guidance and support is available and is supported by over 220 organisations, although few are in Scotland specifically (Willis 2002). Willis mapped 47 groups offering open access support and a range of other networks but highlighted that at present there is no centralised collection of data to assess level of demand and service provided.

³ <http://www.crusebereavementcare.org.uk>

⁴ <http://www.winstonswish.org.uk>

Sibling loss

The above synopsis has focused more on parental death but death of a sibling can have similar responses and outcomes, although sibling loss is not as common (Potts et al 1999). A literature review by Huntzinger (1995) has two recurrent threads; one that is focused on the relationship between the siblings and the consequences of the loss, and a second focusing on the loss of 'attention' because of the parent's own grief reactions (Potts et al 1999, McCowan and Davies 1995). Robinson and Mahon (1997) highlight (although this is related more to adult siblings) that specific changes occur relating to self-perception and changes in world view, which will be governed by the context surrounding the child and the stage of their development, the family system and the nature of the death.

The role of the surviving child may change, as may the relationships within the family and as such should be considered when dealing with sibling loss. More aggressive behaviour in the surviving child(ren) has been identified, particularly in younger children and has been interpreted as a need for attention (McCowan and Davies 1995). Similar analysis carried out by Birkenbaum (2000) highlights the need for better assessment of children to establish the problems associated with the death of a sibling. Potts et al (1999) demonstrate the value of a 'Treasure Weekend' as one means by which bereaved siblings can express their grief, remember their sister or brother and potentially move on. Such events may also have a positive impact on family functioning.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Study	Papers	Total
Childhood Bereavement		
Systematic or systematic type review	Scneiderman et al (1994), Centre for Advancement of Health (2003)	2
Literature or literature type review	Curtis and Newman (2001), Huntzinger (1995), Lowton and Higginson (2002), Ribbens McCarthy and Jessop (2005)	4
Experimental/RCT	Sandler et al (2003)	1
Case Control/Cohort	Lloyd-Williams et al (1998)	1
Observational (no comparison group)	McCown and Davies (1995), Birkenbaum (2000), Harrison and Harrington (2001), Kalter et al (2002), Silverman and Worden (1992)	5
Mixed methods	Williams (1998)	1
Qualitative		
Opinion/text	Black (1996), Black (1998), Brown (2004), Corr (2003-2004), Corr (1999), Holland (2003), Melvin and Lukeman (2000), Potts et al (1999), Robinson and Mahon (1997), Schuurman (2004)	10
Books/Book Chapters, Reports etc	Bunce and Rickards (2004), Willis (2002)	2
TOTAL		26

Key Messages in Childhood Bereavement

Issues of bereavement need to be integrated into mainstream services and policies for young people rather than being isolated specialist services. They may also need to be targeted in areas of deprivation and disadvantage.

A range of services needs to be available from telephone contacts through community and peer support groups to other related therapeutic interventions provided by a spectrum of public and voluntary organisations. A framework of such services covering the bereavement journey would be useful to the bereaved and to practitioners.

Parental bereavement may increase risk of social, material and mental health deterioration in children.

The consequences of the death of a sibling should be considered, particularly within the context of the family group and the stage of development of the surviving child.

Identified risk factors should be used to target those children/families most likely to develop emotional/behavioural problems.

Education about death and bereavement needs to be more widely and systematically included in schools. This should also involve specific support and input to teachers.

Adolescent Bereavement

It is suggested, in the literature reviewed, that adolescents have specific needs when considering grief and bereavement. Some of the work already reviewed in the childhood bereavement section covers children up to the age of 16 or 18 and as such would cover the period of adolescence. However, there is a body of literature related specifically to adolescents and it is estimated that about 6% of 16 years olds will have lost a parent and 5% a sibling, with other losses, such as grandparents much higher (60-70%). Only a small number of adolescents, 7-8%, may never have experienced any form of loss through death (Harrison and Harrington 2001).

Mearns (2000), from a palliative care perspective, highlights how adolescents suppress or deny their emotions more so than other children. She points out that due to this period of development being a time of physical and emotional change, specific attention needs to be paid to adolescent needs, commencing before death. The challenges to dealing with adolescents' grief is noted by Balk (1996), who appears to be a key writer and researcher in this area. Understanding and supporting adolescents needs to take account of their developmental stage, their coping skills and the broader psychosocial culture in which it occurs. Christ et al (2002) clearly support the need to take account of developmental stage and coping skills. They provide areas of risk and recommendations and 'what to say' for professionals through the periods of terminal illness, death and family rituals and bereavement and reconstitution. They consider that clinicians need to appreciate the demands of death and bereavement and how this intersects with the child's developmental stage.

Servaty-Seib and Hayslip (2003) suggest that the rituals associated with death (viewing the body and facilitating grief) are not highly rated by adolescents in facilitating grief responses. They report that adolescents may have more issues related to changes in relationships and the way in which they feel they present to others, a finding supported by all the other papers in this theme. Such a finding would appear to reflect the stage of

development of these young people are at. Adolescents themselves however, may not see the need for professional help and the majority would use relatives and friends to talk with about their experience, although those with multiple losses may have more depressive symptoms and need to be targeted (Harrison and Harrington 2001). Because of their stage of development it may be considered that for adolescents, there is a potential positive dimension with enhanced spiritual development as they question death and search for meaning in life (Batten and Oltjenbruns 1999).

Therefore addressing the needs of adolescents may demand a range of different or adolescent appropriate interventions, in addition to talk related therapies. For example, Dalton and Krout (2005) report the success of a short songwriting music therapy course and Kershaw (1998) the potential value of mind mapping.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence Adolescence	Papers	Total
Systematic or systematic type review		
Literature or literature type review or	Mearns (2000)	1
Experimental/RCT		
Case Control/Cohort	Dalton and Krout (2005)	1
Observational (no comparison group)	Harrison and Harrington (2001), Servaty-seib and Hayslip (2002- 2003)	2
Mixed methods		
Qualitative	Batten and Oltjenbruns (1999)	1
Opinion/text	Balk (1996), Christ et al (2002), Kershaw (1998)	3
TOTAL		8

Key Messages in Adolescent Bereavement

Adolescents may have specific needs (different to children or adults), particularly related to how they feel versus how they present themselves to others, which may be difficult to resolve. Such difficulties may benefit from adolescent appropriate interventions.

Having a range of informal and formal supports particularly across home and friends and also within education, health and social care settings.

There is a range of risk and protective factors that could be useful for assessing adolescents' likelihood of coping successfully with loss, particularly of a parent or sibling. In addition, it is essential to view these in the light of an understanding of the stage of development.

Education settings

The literature reviewed within the childhood and adolescent themes indicated the need to consider how death is dealt with in curricula, the impact of death on education, and how bereaved children and adolescents are supported in school/college/university environments. The review by Lowton and Higginson (2002) formed part of a series of papers dealing with this topic.

Other work by these authors (Lowton and Higginson 2003) highlights the uneven provision of school-based counsellors, education and training for teachers, bereavement policies and other bereavement support services in the UK, whilst the number of bereaved pupils and students is high. Although they highlight a local child bereavement service there would appear to be concerns expressed by teachers that little ongoing communication occurs between health and social care agencies and schools. Societal views of death, the local setting of the school and the degree of family involvement apparently influence teachers' responses. However, there are often practical ways and materials available to assist. The conclusion of Lowton and Higginson (2003) is that training teachers alone to deal with bereavement may not be most effective, and the provision of support through external agencies should also be available. Teaching death, dying and bereavement in health care courses was identified as difficult (see also Chapter 17: Education and Professional Development). Therefore, there is added difficulty in teaching these subjects to children that needs to be considered.

Holland (1997), reporting a broader survey of schools in Humberside, demonstrated a limited depth of training and a perceived need by teachers for more formal policies or procedures, considerable noted problems in the children who had been bereaved and a varied approach to and linkage with other agencies. Such findings are reported in other cultures (Papadatou et al 2002, in Greece, Servaty-Seib et al 2003, in the US), although there are also distinct educational, ritual and family orientated factors which may not be present in the UK. Holland (2003) went on to develop and introduce a structured interactive training package *Lost for Words*. An associated

evaluation indicated that more schools now had teachers trained and a planned response and policy on bereavement, although as yet no assessment of impact. Papadatou et al's (2002) survey also stimulated the development of a wider programme of support, entitled *Sensitization and training of educators and health care professionals in supporting seriously ill and bereaved children*. As in the *Education for Health Professionals* chapter (17) there is an acknowledged need for a training programme that is initially delivered to selected trainers.

In support of such programmes, Lowton et al (2004) and Servaty-Seib et al (2003) identify numerous practical approaches that can be used by teachers and schools to deal with bereavement. These range from methods and approaches to improve communication with children and families, to ensuring involvement of pupils in decision making. A range of web-based, video/CD and printed materials are highlighted. There are also other local approaches to support available, such as The Grief Centre (Manchester Area Bereavement Forum⁵), which has a School Liaison project aimed at supporting schools in dealing with bereavement; and the Childhood Bereavement Network⁶, which seeks to enhance the quality of support, including that to support teachers.

Balk (2001) offers a very different perspective to the above by suggesting that universities should have a bereavement centre which deals with supporting students who are grieving and also undertaking research into grief and bereavement. He believes that students are hidden grievers (Balk 1998) whose mourning is disenfranchised (Doka 1989), who will not make use of other pastoral care, and who see counselling as an indication that they are not coping and are in need of mental health support. His argument is persuasive when considering that the potential number of students who may be 'recently' bereaved is high and the extent to which their bereavement

⁵ <http://mabf.org.uk>

⁶ <http://www.ncb.org.uk/cbn>

may impact on retention on their course. However, a bereavement support programme (Balk 1998) for this group showed limited impact within the short term.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Bereavement and Educational Settings		
Systematic or systematic type review		
Literature or literature type review	Lowton and Higginson (2002)	1
Experimental/RCT		
Case Control/Cohort	Balk et al (1998)	1
Observational (no comparison group)	Holland (1997), Holland (2003)	2
Mixed methods	Papadatou et al (2002)	1
Qualitative	Lowton and Higginson (2003)	1
Opinion/text	Balk (2001), Servaty-Seib et al (2003)	2
Books, Book Chapters, Reports	Lowton et al (2004)	1
Pre 1990 papers	Doka (1989)	1
TOTAL		10

Key Messages in Education Settings

All schools and teachers need to have available resources (including training) to deal with bereavement in the school/classroom, this should include the availability of policies and procedures.

Schools and teachers must be part of a network of agencies that would be available to support children before and after the death of a significant other.

Death and bereavement should be part of the curriculum in primary and secondary settings.

Universities may need to approach bereavement in different ways from that of primary and secondary schools.

Children in Hospital

Whilst the extent of literature in this section is small and evidence level low, it was considered an important area to cover. This was so particularly following revelations at Alder Hey and Bristol, among others, and the subsequent inquiries (Royal Liverpool Children's Inquiry, Redfern 2001; The Report of the Bristol Royal Infirmary Inquiry, Kennedy 2001), which highlighted poor practice, especially in relation to dealing with tissue and organ retention. The inquiry at Alder Hey raised the profile of consent to post mortem and organ retention and highlighted the role of clinicians in seeking consent, providing information and respecting parents' wishes. The inquiry recommended the establishment of bereavement advisors to carry out this role, certificated through recognised training courses (Chapter 12).

Sque, Long and Payne (2004) in a subsequent study to explore organ retention, outline the need for involvement and choice by families, a change of attitudes and education in health care organisations, support for a team approach, and flexibility across boundaries in respect of tissue and organ retention. They propose an interlocking model of bereavement services that involves information giving, referral processes, liaison between teams and appropriate interventions; all supported by practitioners and volunteers. Jennings (2002) also highlights the outcomes of the Alder Hey inquiry and the recommendation of appointing bereavement advisors to ensure that families have the opportunity to discuss, question and be informed of practical issues. She reports an evaluation of eight bereavement support posts with broad findings that clinical staff welcomed the support provided and believed that there were positive outcomes for care.

If, as Stack (2003) reports, approximately 25% of deaths in post-neonatal children occur in Paediatric Intensive Care Units (PICUs) then it would seem appropriate to target such clinical areas. He reports on the publication of the Paediatric Intensive Care Society standards published in 2002. These standards provide practical advice for PICU staff and acknowledge a lack of structured training about bereavement care for medical or nursing staff (as

does Cook et al 2002 and Costello and Trinder-Brook 2000). Colville (1998) in an earlier paper, prior to Alder Hey and Bristol, also demonstrated that there was a 'patchy' approach to dealing with psychological issues related to bereavement in PICUs for both staff and families.

As many deaths in PICUs are unexpected or 'difficult' there is the likelihood they will be more distressing to deal with (Cook et al 2002) and the parents may be vulnerable to future problems (Stack 2003). However, Sirkia et al (2000) found no difference in coping between parents of children receiving terminal care or active treatment for cancer suggesting that in other settings the type of death may not always influence outcomes. Identifying those parents or relatives who may be experiencing 'pathological' grief is considered difficult and often assessed through absent or excessive reactions resulting in GP contact for further follow up (Cook et al 2002). Developing and providing guidelines for staff in dealing with and assessing families of critically ill children can be beneficial (Lipton and Coleman 2000).

Support and education for staff appears to be a key factor in most of the papers reviewed. Costello and Trinder-Brook (2000) identify the significant emotional investment that nurses make to this period and the lack of available formal, and sometimes informal, mechanisms that exist to support them. It also appears that there is still a perception that showing emotions at this time is 'unprofessional'. Meert et al (2001) seek to demonstrate that the approach of nurses at and around the time of death can be influential in the way parents cope with bereavement. The parental perception of an uncaring emotional attitude had a detrimental effect on both short and long term bereavement.

The need for families to be involved in all aspects of care must also be raised as the majority of the above papers highlight the need for honesty and engagement. However, there is limited evidence on the extent of such involvement, for example, the presence of parents during resuscitation. A brief report on the European Society of Paediatric and Neonatal Intensive

Care website⁷ considers the issues relating to parents being present during resuscitation in PICU and indicates some positive outcomes

Stack (2003) concurs that it may be useful for parents to know that 'everything was done for their child' although it must, as in the situation with adults examined in the *Acute, Hospital Care* chapter (15), be a considered judgement that is undertaken with the parent and that they are supported throughout by a member of staff.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Bereavement and children in hospital		
Systematic or systematic review		
Literature or literature review		
Experimental/RCT		
Case Control/Cohort		
Observational (no comparison group)	Colville (1998), Meert et al (2001), Sirkia K et al (2000)	3
Mixed methods		
Qualitative	Costello and Trinder-Brook (2000), Jennings (2002)	2
Opinion/text	Cook et al (2002), Lipton and Coleman (2000) Stack CG (2003)	3
Books, Book Chapters, Reports etc	Redfern (2001), Kennedy(2001), Sque, Long and Payne (2004), Paediatric Intensive Care Society Standards (2002)	4
TOTAL		12

⁷ http://www.espnice.de/downloads/Parent_Resusc.pdf

Key Messages in Children in Hospital

There is a perceived need to establish some form(s) of educational provision, for both specialist bereavement advisors/support staff and more generally for all clinical staff who may encounter death, dying and bereavement in children.

The provision of specific bereavement advisors may be beneficial but there is limited evidence of the effectiveness of such posts.

Parents need good information and should be involved in all aspects of their child's care. They may also wish to be present for some procedures that are at present closed off, such as resuscitation.

Organ and Tissue Donation

It was difficult to know how to deal with the small number of papers initially identified and selected on organ and tissue donation. As the issues raised by Alder Hey and Bristol were related to children and have been highlighted in the childhood section it seemed appropriate to continue to this topic, albeit with awareness that organ and tissue donation can cover other adult areas of care. It became clear that some of the selected papers were dealing with the process of gaining consent and authorisation (for example Scott's letter dated 24th November 2003 – see references). Providing any form of review on this process seemed unhelpful as there is obvious on-going work that is already well grounded and there is considerable writing on organ and tissue donation per se. However, organ and tissue donation does highlight the question of how consent may be given when relatives are about to be or are newly bereaved and their level of understanding, particularly if that death is sudden or unexpected (Brazier 2003).

Sque et al (2005) demonstrate that the quality of hospital care can impact on the family's decision to consent. Often consent is not given because families are not asked, although they later indicate they would have not minded being asked (Wellesley et al 1997). Crucial to the quality of the experience in Sque et al's (2005) study were nurses and transplant co-ordinators with medical staff either enhancing or detracting from this baseline. One finding which emerged was the involvement of children in the decision making process. Children were present and actively participated in a third of evaluated events and at times the decision hinged on 'what the child thought'. The question of impact and support for such children is thus raised but not answered.

The grief trajectory for those evaluated by Sque et al (2005) appears to be, on the whole, 'normal' with a reduction in symptoms over time (see also Cleiren et al 1993). Evidence suggests that organ donation (or refusal) itself may have little impact on the subsequent grief process (Cleiren and Van Zoelen 2002). However, there are issues raised about information and the

way in which it is given (Cleiren and Van Zoelen 2002; see also Chapter 5: *Parental (Perinatal) bereavement*, in respect of post mortem). If information was correct, given in complementary ways and in a responsive manner then it had a lasting positive impact. The converse created a negative impact. Questions often remained that had not been asked due to the shock of bereavement, these were still important but answers were perceived as unavailable.

Sque and Payne (1996) in an earlier study identify the emotionally charged nature of donor care and the constant conflict and resolution process that relatives work through related to the decision making surrounding organ donation. Knowing the person's wishes can be helpful in this but the extent to which individuals consider making this clear may be limited (Tymstra et al 1992), although Elding and Scholes (2005) report a marked increase in the UK of those registered on the Organ Donor Register (20% of UK population).

The model of dissonant loss proposed by Sque and Payne (1996) may be helpful for practitioners as it could help to illuminate this difficult time period and suggest appropriate and timely responses in caring for families/relatives. Suggestions include: communicating with appropriate non-clinical language, providing the information at the right time, and paying attention to reactions. Such approaches are similarly described by Cleiren and Van Zoelen (2002).

Enhancing the communication skills of those involved in caring for the organ donor and relatives/family and those requesting organ donation would therefore seem essential. The use of the European Donor Hospital Education Programme (EDHEP) is reported by Morton et al (2000). This brief workshop based approach has been shown to enhance communication skills in breaking bad news and making a request for organ donation. Morton et al (2000) demonstrate such improvement in doctors but not nurses and this raises the question of either different needs within each professional group or perceived difference in role at this time, although the need for further education is not questioned. Education is identified as crucial by several recent papers (Sque, Long and Payne 2004, Elding and Scholes 2005; Matzo et al 2003)

both to enhance communication and so reduce problems surrounding bereavement in families but also to assist staff to overcome the uncertainty surrounding donation.

Specific interventions for families/relatives of those who donated tissue or organs appear to be limited. A paper by Vajentic and Calovini (2001) outlines a group support programme which highlights the benefit of sharing experiences with those in a similar situation, a finding reported in other settings as well. There may also be support groups for those families and parents of the bereaved where organs and tissues were retained without consent. However, these have a very distinct focus and were therefore not reviewed here.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Organ and Tissue Donation		
Systematic and systematic type review		
Literature and literature type review		
Experimental/RCT	Morton et al (2000)	1
Case Control/Cohort		
Observational (no comparison group)	Sque et al (2005), Cleiren et al (1993), Cleiren and Van Zoelen (2002), Elding and Scholes (2005), Wellesley et al (1997)	5
Mixed methods		
Qualitative	Sque and Payne (1996), Tymstra et al (1992)	2
Opinion/text	Brazier (2003), Vajentic and Calovini (2001), Matzo et al (2003)	3
Books, Book Chapters, Reports etc	SEHD Letter (2003), Sque, Long and Payne (2004)	2
TOTAL		13

Key Messages in Organ and Tissue Donation

There is little evidence that organ donation (or conversely refusal) has any significant impact on the grieving process over the long term.

There is a need to ensure communication and information is geared to the individuals and the timing and content are appropriate.

Education related to tissue and organ donation, for those practitioners working in settings likely to encounter donation is viewed as desirable.

The availability of voluntary organisation support is apparently limited in respect of organ and tissue donation.

Chapter 5: Parental Bereavement

This chapter begins by dealing with bereavement in parents. The issue of perinatal bereavement is covered below as a distinct component. However, it is accepted that there are often overlaps and some of the research or reports related to the death of children cover stillbirth and neonates. A considerable range of writing and research in this area is apparent demonstrating the significant impact of children's deaths on parents, identified as greater in intensity than the death of a partner or parent for adult children (Seecharam et al 2004; Murphy et al 2002) and having a significant impact on health (Stroebe et al 2001; Znoj and Keller 2002). Although the quantity of material is significant, the levels of evidence into which the majority falls are low.

De Vries et al (1994) draw upon Rando's (1986) work to highlight the range of influencing factors in determining grief responses to the death of a child, namely: the untimeliness of the death, the nature and quality of the lost relationship, the role the deceased played, the characteristics of the death and the social support system. They outline a range of issues which affect each of these factors and also point out the need to examine the loss against the age of the child (infant, young child or adult child) as these impact in different ways on 'family' functioning and development. Murray et al (2000) identify some similar, more specific risk factors: lack of perceived social support, ambivalent relationship with the baby, particularly traumatic circumstances surrounding the death, other difficult life circumstances, difficulty with coping in the past, problematic individual characteristics and unsatisfactory relationships within the nuclear family.

If the death is sudden then parents may develop post-traumatic stress disorder (PTSD) (Janzen et al 2003-2004). Adolescents may be seen as being at particular risk of dying from accidents and suicide (Davies 2001, Murphy et al 2002). Davies, drawing on a range of evidence, suggests that parents of adolescents are at increased risk of responding to death outside

the 'normal' responses. Possibly due to the emotional and relationship changes occurring for the adolescent, and within the family at that time. However, much of the evidence offered fails to differentiate adolescents as a distinct group. In addition Dyregov et al (2003) suggest that the issue is one of traumatic death rather than one of age. Murphy et al (2003a) conclude that the type of traumatic death is also not that significant. Deaths in younger children (for example from SIDS) may also occur when parents are younger and have less established partnerships and coping skills.

Irrespective of age, it appears that parents, in Western cultures, who lose an infant, suffer a reduced quality of life over a long period (Dyregov 1990). The Centre for Advancement of Health review (2003) indicate that it can take 3-4 years for parents to accept the death of a child. It also suggests that parental health post loss is diminished, particularly for fathers over the long term. The differences between men and women in respect of grief have been well reported with a variety of explanations related to different: attachment to the child, methods of coping, emotional responses and social situations (Dyregov 1990; Murphy et al 2002).

The search for meaning and its reconstruction after the death is also considered an important factor (Wheeler 2001; Klass 1997) with keeping the memory of the child alive resulting in more positive changes. Davis et al (2000) question this search for meaning as appropriate, particularly when the events surrounding the death and the death itself 'shatter deeply held worldviews'. Klass (1997) proposes that grief does not end with the severing of bonds with the child but continues through integration of the child into the parent's life in a different way than before the death. Such changing perspectives on parental bereavement are noted by Davies (2004) who indicates that models of bereavement have moved from detachment from the dead to maintaining attachment in some form.

The support for parents from health professionals is reported as variable (Dyregov 1990), the extent to which this has changed is questionable (see for example perinatal bereavement below). Janzen et al (2003-4) illustrate

parents' experiences and their advice to professionals (Police, nurses, doctors, coroners, social workers/crisis counsellors, funeral directors and clergy). They divide this advice into three areas: instrumental assistance (e.g providing access, allowing time, respecting decisions), provision of information (e.g details of death, what to expect and do, rituals and memorials) and compassion and empathy (e.g give control, actively listen, be present, respect for the child's body, respect faith). One parent stated *'It is amazing what an impact the actions/reactions of others can have during this traumatic and very vulnerable time. I remember very clearly the things that were said and done which were comforting. I remember just as clearly, in fact, perhaps more clearly, the things that were said and done which were hurtful and upsetting'*. This illustrates the impact of professionals at the time of death and afterwards and the need for better training and education across professional groups (a finding supported by Oliver et al 2001).

Murray et al (2000) describe an intervention to assist parents to adjust to the loss ('normal' grief) using an Australian programme known as *An Ache in their Hearts*. This well-considered controlled study using a trained grief worker and validated resources demonstrated that parents do benefit from such intervention and those at most risk are likely to benefit most. Differences in time for benefit were noted between mothers and fathers, with mothers benefiting earlier than fathers, again suggesting different patterns of grief for men and women. Although not confined to parents, Schut, Stroebe, van den Bout and Terheggen (2001) indicate that men may benefit from interventions that help them to express their grief, mothers are also more likely to attend grief support groups (Laasko and Paunonen-Ilmonen 2002) and social support, of all types, can have an impact on bereavement (Thuen 1997). Rowa-Dewar (2002) in a review of interventions, indicates that they should be targeted at parents who are at high risk, rather than any blanket coverage, taking account of individual and gender issues.

The studies by Laasko and Paunonen-Ilmonen (2002) and Thuen (1997) highlight the potential cultural differences between Scandinavia and the US and the impact this may have on any comparison of results. (Many other

cultural differences and similarities exist. For example, see Bonnano et al 2005; Malkinson and Bar-Tur 1999.) Dent et al (1996), in a UK based study, also suggest that parents want to interact with others who have suffered the same loss (Klass 1997), although Murphy et al (2002) found no evidence that personal and family prayer and church attendance, amongst other social/community resources, improved parents' outcomes. Geron et al (2003) assessed the value of group intervention for bereaved parents run by the Ministry of Defence in Israel, and concluded that these are most beneficial for those seeking to form relations with others in the same situation. Groups, they suggest, offer identification, empathy and a sense of belonging and provide opportunity to express feelings and learn from others. Riches and Dawson (1996) agree that support groups can offer social and cultural resources not now available elsewhere.

Dent et al (1996) evaluated statutory and voluntary services in England and Wales for those who had lost a child (mainly SIDS). They highlight that while most emergency and hospital services were identified as good (see also Seecharan et al 2004) there was a lack of information and communication which could have helped before and after the death. Of some significance was that parents could not understand why they were not asked about organ donation (SIDS). GPs and Health Visitors surveyed indicated a desire to be actively involved in follow-up of parents although they felt a need for more training and information. Other groups surveyed (A&E staff, emergency services) also expressed a need for further training. Voluntary agencies identified health visitors as a group they worked with particularly but would have liked more information on coordination with health professionals. What is also of interest in this survey is the blocking carried out by ethics committees, paediatricians and GPs.

Finally, returning to the differences and similarities between men and women. These are explored by Wing et al (2001) who identify, from the available evidence, a convergence of responses and symptoms over time. Mothers are identified as expressing more intense grief than fathers and for a longer period (e.g. Schwab 1996). Wing et al (2001) highlight the effects on

the couple and the value of providing therapy aimed at the couple, as much as aimed at the individual parents. The use of the Grief Experience Inventory is suggested as a useful tool to facilitate discussion between parents (Schwab 1996) at the outset of such therapy. The impact of a child's death may also be felt in the work place as parents' seek to cope with the demands of work to maintain economic status whilst at the same time struggling with their grief (Klass 1997). It is not known what arrangements employers make to facilitate 'return' and how colleagues can assist in this process, it may be that this is also compounded by the masculine culture of work and may be experienced differently by mothers and fathers.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Bereavement in Parents		
Systematic or systematic type review	Centre for Advancement of Health (2003), Rowa-Dewar (2002)	2
Literature or literature type review	Davies (2004), DeVries et al (1994), Dyregrov (1990), Wing et al (2001)	4
Experimental/RCT		
Case Control/Cohort	Znoj and Keller (2002), Murray et al (2000)	2
Observational (no comparison group)	Bonanno et al (2005), Davis et al (2000), Dente et al (1996), Dyregrov et al (2003), Geron et al (2003), Murphy et al (2002), Murphy et al (2003a), Oliver et al (2001), Schwab (1996), Seecharan et al (2004), Thuen F(1997)	12
Mixed methods		
Qualitative	Janzen et al (2003-2004), Klass (1997), Laasko and Paunonen-Ilmonen (2002), Malkinson and Bar-Tur (1998), Riches and Dawson (1996), Wheeler (2001)	6
Opinion/text	Davies (2001)	1
Books, Book Chapters and Reports etc	Rando (1986), Schut et al (2001), Stroebe et al (2001)	3
TOTAL		30

Key Messages in Parental Bereavement

There is evidence of a range of factors that influence grief and bereavement in parents, which need to be assessed and addressed by all professional groups who may deal with death and dying in children.

Co-ordinated interventions using validated programmes of support and trained staff may make a difference to the trajectories of normal grief and reduce the likelihood of complicated grief.

Self-help groups can be beneficial for parents and they need to be guided and given appropriate information.

Good quality information should be available for parents, that informs them of what is happening/happened to their child and practical issues and contacts after the death.

Identification and follow up of parents, particularly those who experience a sudden and traumatic death should be developed and co-ordinated within health and social care.

Education for health and social care professionals, voluntary agencies and others should be available.

Perinatal Death

We identified, and initially selected, a considerable number of publications in this area (42). The presence of a negative Cochrane review on interventions suggested that we might need to incorporate a greater range of literature if any key messages were going to be identified. Additionally, other significant papers became apparent early in the review of this area and where possible were accessed. The considerable number of papers exploring, describing and researching perinatal loss may be due to an increasing interest in this subject in Western countries, as family size diminishes and the loss of a baby becomes increasingly significant. The work of Kennell and Klaus (1970) provides an historical marker for many of the papers reviewed and suggests that research and writing in this area has only developed significantly since then.

The types of death included range from conception to the first month after birth (Rybarik 2000) consisting of early pregnancy loss (miscarriage) and late pregnancy loss (stillbirth, perinatal loss, neonatal death) (Janssen et al 1996). However, not all are recorded (Lovell 2001) and as McCreight (2004) and Lovell (2001) note there may be hospital based and within hospital differences related to dealing with the outcomes from early loss, although this may have changed since Redfern (2001) and Kennedy (2001) reported. In 2003, 682 deaths were notified to the Scottish Stillbirth and Infant Death (SSBID) Survey (compared with 672 in 2002), comprising:

- 121 late foetal deaths (infants born dead at 20-23 weeks of pregnancy or earlier in pregnancy if the birthweight is 500g or more);
- 296 stillbirths (5.6 per 1,000 total births);
- 178 neonatal deaths (deaths in the first four weeks of life)(3.4 per 1,000 live births); and
- 87 post-neonatal deaths (deaths after the first four weeks but before the end of the first year of life)(1.7 per 1,000 live births. 88% occurred before six months of age with SIDS accounting for 42% of deaths).

Approximately a third of the papers initially identified were text and opinion. However, a small number of reviews were identified, including a Cochrane review (Chambers and Chan 2005), which in itself highlights the extent to which perinatal death is a distinct area of concern. Unfortunately, the review by Chambers and Chan (2005) highlights the 'difficulty and inadequacy of research in the area of grief support surrounding perinatal death' (p3). Although they indicate no evidence exists to support the effectiveness of interventions in this bereaved group, it is contended that there is a broader range of evidence which illustrates the main areas of concern. There is a clear indication that a small percentage of women may be at greater risk of developing depression, anxiety and complicated grief (Chambers and Chan 2005; Bartellas and Van Aerde 2003; Lasker and Toedter 2000; Toedter et al 2001; Janssen et al 1996;1997)

Frost and Condon (1996) highlight the psychological sequelae of miscarriage and suggest that, from their extensive critical review of a significant number of papers, it is often not recognised by health professionals and may contribute to subsequent depression, anxiety and post-traumatic stress disorder. Despite such evidence Nikcevic (2003) states there is no routine follow-up care for women after miscarriage in the UK despite depression rates reported between 8-48% in the first 6 weeks and anxiety levels of 22-45% up to 6 months. Descriptive studies identified by Nikcevic show considerable appreciation and perceived benefit from offering follow-up. However, although there is no evidence of effectiveness of psychological/counselling interventions alone, Nikcevic (2003), drawing on other research work, shows that a combination of medical and psychological support can be beneficial. It is interesting to note that one of the RCTs

⁸ <http://www.isdscotland.org/spimmr>

assessed by Chambers and Chan (2005) i.e. Lilford et al (1994), reports on the beneficial effects of the obstetrician having feedback on performance from a psychoanalytical psychotherapist after joint consultation sessions and the value of clinician sessions as opposed to dedicated psychotherapy sessions.

Lasker and Toedter (2000) comment that outcomes in respect of grieving may be related more to overall satisfaction with the attention given during hospital stay, than to specific interventions, which is also noted by Chan and Chambers (2005) as potentially more cost effective than provision of specialist services. Wong (2003) in a well designed and reported qualitative study demonstrates clearly the perceived discrepancy between parents' perceived needs and service provision in the community. The Health Visitor is identified as the professional in the community who should be key/lead carer and that a formal process for notification should occur. The type of follow up may vary (Friedrichs et al 2000) although there are recommended features of telephone follow up which may identify those at most risk so that appropriate referrals can be made.

As part of any perinatal death, parents are often asked to consent to a post mortem to determine the nature of death in the foetus or baby and perceive the benefits of such an examination as assisting in improving understanding of the reason for the death (Rankin et al 2003). Despite this perspective Snowden et al (2004), although possibly related more to post mortems for trial data, highlight the reluctance of staff to request post mortems, despite the potential that more parents may be willing to give permission for altruistic reasons. Parents also request that medical terminology and concepts should be fully explained and opportunity to ask questions at a later date built in (Rankin et al 2003). This may form part of the medical support identified by Nikcevic (2003). Knowles (1994) provides a distinctive Australian rural view of how a pathologist may also form part of the multiprofessional team to communicate with the family and disseminate information about perinatal death and post mortem.

However, there is evidence of considerable variation in the way mothers grieve and search for meaning (The Centre for Advancement of Health 2003). Validating and remembering the loss may assist in this process through photographs, mementos, foot and hand prints, locks of hair and receiving blankets and attending funerals and memorial services (Bartellas and Van Aerde 2003, Gensch and Midland 2000). Gensch and Midland (2000), amongst others, are emphatic in promoting the option to see and hold the dead baby, however, more recent research by Hughes et al (2002) highlights the potential negative outcomes that such a 'forced' choice can have on women. The same may be true of the other validating and remembering approaches.

These are also questioned by Lundqvist and Nilstun (1998) who describe the dilemmas for nurses in neonatal ICUs when parents are reluctant or refuse to touch or hold their dead baby. In the same Swedish context, Saflund (2004) finds no such negative perspectives. Although no measurement of outcomes is undertaken parents reported the value of holding and spending time with the dead baby. Whilst there is some questioning of such approaches a further consideration that may impact on such practice is that of culture and religion, which needs to be understood and addressed by staff (Hebert 1998). On a more practical note, Mander and Marshall (2003), taking an historical perspective on the photograph/picture for stillbirths or neonates, highlight the need for quality in the photography, a factor probably not incorporated in many midwifery programmes.

Cultural and religious differences are particularly important in relation to perinatal deaths as different rituals and relationships exist. Lovell (2001) identifies a lack of religious engagement with stillbirth and miscarriage which often results in parents gaining little spiritual support from this direction. Hsu (2004), Chan (2003) and Van and Meleis (2003) all provide examples of different cultural, religious and ethnic factors that impact on perinatal death. Pector (2002) in a fascinating review of twins highlights, from a cross cultural perspective, the impact of twin deaths and how this may create disenfranchised grief for parents if one twin is lost and belief that the other

twin may have the spirit of the deceased. Pector (2004) continues to examine loss in multiple births in a western context, through on-line interviews with those who have experienced loss following multiple births. The findings suggest that there are common issues to any single birth loss but the extent of decision making will be greater in multiple loss as parents may have to juggle feelings and decisions.

Within the perinatal bereavement literature there is also a distinctive component related to men. Janssen et al (1996) highlighted the potential for delayed grief in men and chronic grief because of lessened interventions at all points (Lasker and Toedter 1994). McCreight (2004) and Puddifoot and Johnson (1997) illuminate these through qualitative studies and consider that the present societal, health care organisations and voluntary group processes and procedures do not assist men to grieve and need to be addressed. Puddifoot and Johnson (1997) graphically illustrate the lack of engagement in the health care setting. Alderman et al (1998) also illustrate the different experience of grief in male partners and highlight the need for this to be considered more fully.

Perhaps any consideration of male or female experiences should be within a family context. Whilst attention has been paid to women and some to men, less has been so to siblings and grandparents. Oikenen and Brownlee (2002) reviewed such work and describe the potential benefits of family therapy. As grieving usually goes on in some form of family unit, different 'stories' of each family member can be helpful to share to develop understanding of each others' loss and subsequent support.

The final significant group to be considered in the selected literature is adolescents. Whilst adolescence and bereavement is dealt with more fully in *Childhood bereavement* (Chapter 4), there are significant factors identifying this group as at particular risk, with perinatal loss being high in this age group (US figures). Welch and Bergen (2000) describe the multiple layers of disenfranchised grief (from Doka 1989) that adolescents will experience. They contend that due to the emotional, physical and social changes

occurring in adolescents that they need specific age-appropriate support. Additionally there would appear to limited information and education to assist these individuals.

Irrespective of type of loss it places a heavy demand on staff. To provide good quality care it is suggested that colleagues and the organisation need to be supportive (Moulder 1999). The provision of education is important but must take into account the professional's own attitudes and reactions. Assessing their level or stage of development is, Askey and Moss (2001) state, essential so that an appropriate programme for learning can be implemented.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Perinatal Death		
Systematic or systematic type review	Centre for Advancement of Health (2003), Chambers and Chan (2005), Toedter et al (2001)	3
Literature or literature type review	Bartellas and Van Aerde (2003), Condon (1996), Frost and Janssen et al (1996), Lasker and Toedter (2000)	4
Experimental/RCT	Lilford et al (1994)	1
Case Control/Cohort	Hughes et al (2002)	1
Observational (no comparison group)	Alderman et al (1998), Chan et al (2003), Janssen et al (1997), Lasker and Toedter (1994), Rankin et al (2003)	5
Mixed method		
Qualitative	Askey and Moss (2001), Hsu et al (2004), Lundqvist and Nilstun (1998), McCreight BS (2004), Puddifoot and Johnson (1997), Saflund (2004), Snowden et al (2004), Welch and Bergen (2000), Van and Meleis (2003), Wong et al (2003)	10
Opinion/text	Friedrichs et al (2000), Gensch and Midland (2000), Hebert (1998), Knowles (1994), Lovell (2001), Mander and Marshall (2003), Moulder (1999), Nikcevic (2003), Oikenen and Brownlee (2002), Pector (2002), Pector (2004), Rybarik (2000)	12
Books, Book Chapters and Reports etc	Doka (1989), Kennell and Klaus (1970), Kennedy (2001), Redfern (2001), ISD Scotland (SPIMMR)	5
TOTAL		41

Key Messages in Perinatal Death

There are psychological effects of miscarriage and other perinatal deaths that suggest follow-up care should be available and offered to all women (partners and families). It should contain both informational and emotional support.

Assessment is helpful to identify those at known greater risk of developing depression, anxiety and complicated grief.

The approach to dealing with mothers, parents and families at the time of death is challenging and should be based on individual needs (involving cultural and spiritual dimensions) with validation/memory based interventions available.

Multi-professional education programmes (that includes all members of the team including pathologists, radiographers, nurses, all levels of medical doctors, psychologists, midwives, health visitors, funeral directors) that are evidence informed may be useful in developing greater understanding about dealing with perinatal death in primary and secondary care.

Policies and guidance for dealing with perinatal death at all stages should be at least national in orientation and take account of cultural and sex based differences.

Chapter 6: Bereavement and Families

Kissane and Bloch (1994) defined family loss as a loss of one of its members, whether a nuclear or extended family unit. Most of the studies of families in this section fulfil these criteria, with no same sex family units. In their Melbourne study of 150 families, Kissane et al (1996) stated that five types of families emerged from their data when they measured dimensions of cohesiveness, conflict and expressiveness, using their Family Environment Scale. Two types were identified as dysfunctional; hostile families (because of their high conflict, low cohesiveness, poor expression) and sullen families (who presented with more moderate findings than the hostile type). At the beginning of the study the incidence of the two dysfunctional groups were as high as 30% at six weeks after the loss; however by the 13 months stage, the numbers had reduced to 15%. Termed the intermediate type, 26% presented with midrange cohesiveness, low control and low achievement of orientation.

Although no age or differences were found in their family types, the hostile families had an over-representation of off-spring. Kissane and Bloch (1994) concluded that it was possible to identify those at-risk families that are dysfunctional, by screening families using the family relationship index of the Family Environment Scale.

Dimensions of cohesiveness, conflict and expressiveness were themes reflected throughout all the studies, although a variation of the terms were found. Traylor et al (2003) in their longitudinal study with 63 participants stated that families who appeared to present with more awareness of their emotions and demonstrated an ability to express these emotions with each other reported less intense grief than stoic families. If the family perceived greater cohesiveness and communicated more, then this led to less grief symptoms. A need for families to communicate to share information, ideas, values and beliefs is needed to reduce isolation within the family unit (Fletcher 2002). In their conclusion, Traylor et al (2003) suggested that

having some knowledge of a family's structure and processes could potentially help predict a family's grief pattern after a death has occurred. No differences were found in their study between spouses' death and parental death.

A Dutch study of bereaved family members and close friends of terminally ill patients, compared 189 family members whose relative or friend had died from euthanasia with 316 whose relative or friend had died from natural cases (Swarte et al 2003). Swarte et al (2003) found the openness shown in the euthanasia families resulted in the families' ability to cope more effectively. Kissane and Bloch (1994) concluded similarly in their literature review of family grief over the previous 25 years. Resolution of grief is more effective if a family demonstrates cohesiveness, mutual support, clear communication, emotional expressiveness and have an ability to work through and deal with conflict and adaptability. Unfortunately, the review did not demonstrate any rigour in their systematic approach nor defined search terms.

Looking at predictors of mild anxiety in the weeks before bereavement Higginson and Priest (1996), in their sample of 302 carers in the South of England, stated that there were predictors of anxiety in the weeks before a family's bereavement. Families with a patient who was aged below 45, was disabled or was married were clear predictors. No gender differences were found between husbands or wives. Individuals whose family member had breast cancer were twice as likely to present with anxiety as were individuals whose family member had gastro-intestinal cancer. A small but significant correlation between the increased duration of time the patient was using palliative services suggested that an early referral to palliative services could have a positive impact on a family's anxiety. Professionals should target high risk families who have been caring for younger members, disabled members and married members.

Brazil et al (2002), in a retrospective cohort study of 151 caregivers of bereaved families, reported the home as the preferred location for the family

member's death. They reported that caregivers whose family member died at home fared better than caregivers whose family member had died in an institutional setting. Providing supportive services, which enable home deaths, was emphasised to ensure better health outcomes for the carers left behind. Teno et al (2001) report similar findings in a hospice setting with participants reporting significantly fewer problems with medical care, feeling happier with the quality of care and higher self-efficacy in caring than those in the acute setting. However, although 88.5% of those in hospice care felt informed about the care given to their family member in their last week of life, 1 in 5 felt there was a problem with the co-ordination of this care.

Financial issues from the cost of caring were believed to be prevalent in families whose child had died (Corden et al 2002a; 2002b). Overall the cost of caring for a sick or disabled child, the cost of the funeral and the cessation of social security benefits (as much as 72%) after the child died had a serious financial impact on their lives. Families who had been caring for the child's final days and claiming social assistance had to suddenly seek employment, which was stressful, as the family were also trying to re-group after the death. However, those who had continued to work, having gone back to work soon after the funeral, retrospectively reflected it had been a good decision for them.

Co-ordination of services and appropriate receipt of social security benefits was a major issue identified by Cordon et al (2002a; 2002b) and few parents had received any financial support or advice. Findings of both studies suggested that the financial impact of caring for a sick or disabled child had the potential to remain with the family long after the death. Financial advice and support was needed to support such vulnerable families, which the authors felt could be an integral part of bereavement counselling process. Although a complex process, the authors felt the benefits could have a profound psychological impact on the families' lives.

Overall the majority of literature in this section fell within the lower end of 3 on the JBI scale. Although Kissane et al (1994) suggested that

anthropological, ethnic and religious affiliation had an important influence on a grieving family, none of the studies chose to incorporate this integral aspect of a family within their studies.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Families and bereavement		
Systematic or systematic type review		
Literature or literature type review		
Experimental/RCT		
Case Control/Cohort		
Observational (no comparison group)	Brazil et al (2002), Higginson and Priest (1996), Kissane et al (1996), Swarte et al (2003), Teno et al (2001), Traylor et al (2003)	6
Mixed Methods		
Qualitative	Corden et al (2002a), Corden et al (2002b), Fletcher (2002)	3
Opinion/text	Kissane and Bloch (1994)	1
TOTAL		10

Key Messages in Bereavement in Families

Early referral to palliative services could have a psychosocially positive impact on a family's anxiety.

Providing supportive services which enabled home deaths was emphasised to ensure better health outcomes for the carers left behind.

Support services should identify at-risk families (particularly those who have been caring for younger members, disabled members and married members), which are dysfunctional, by screening families using a tool such as the family relationship index of the Family Environment.

Support services do not need to target families that demonstrate cohesiveness, mutual support, clear communication, emotional expressiveness and have an ability to work through and deal with conflict and adaptability.

Co-ordination of care and services when a family member is terminally ill would be of value; this should include mechanisms for accessing financial advice.

Spousal Bereavement

The majority of the studies on spousal bereavement had a strong bias towards widows and only one explored gay conjugal relationships (Nolen-Hoeksema et al 1997). The remaining studies had a nominal number of widowers included in their samples and were mainly at Level 3 or 4 on the evidence ladder. Older widows and widowers are dealt with in the older people section of this report (Chapter 7). Some of the studies incorporated numerous tools as an integral part of their research process, which made interpretation of the data time-consuming, cumbersome and demanding for the participants. Although no firm conclusions about who suffers more can be made within this sample of papers, post bereavement risk, in terms of mortality, Stroebe et al (2001) suggest it may be greater for widowers (compared to married men) than widows (compared to married women).

Defined, the word spouse usually refers to a husband or wife through marriage, however within this section it is also used interchangeably as a term for an unmarried partner, which included one study of same sex partners (Nolen-Hoeksema et al 1997). The death of a spouse has been found to be one of the most stressful events in an individual's life and most of the studies demonstrated that the majority of widows and widowers grieve the death of their spouse (Zisook and Schacter 1991, Kaunonen et al 2000, and Bonanno et al 2002). Symptoms of stress are reported to decrease over time, although can be most intense immediately after the death. (Avis et al 1991; Lieberman and Yalom 1992; Hyrkas et al 1997). Zisook and Schacter (1991) in their American study of 250 widows and 100 widowers suggested that a sudden or unexpected death was related to more intense grief at this early stage but was no longer apparent at the seven month stage.

Due to the strong bias towards widows, it was difficult to draw conclusions about which gender in spousal loss suffered more. Most of the studies suggested that the death of a spouse had a stronger effect on mortality and/or morbidity for widowers than it did for widows (Martikainen and Valkonen 1996; Martikainen and Valkonen 1998; Bauer and Bonanno 2001).

In contrast, Manor and Eisenbach (2003) found a 10% increase in mortality for widows in the first and second year post bereavement. Studies agreed the younger widow or widower were more vulnerable (Zisook and Schacter 1991; Bauer and Bonanno 2001; Powers et al 1994) as well as those individuals in the lower end of the social spectrum (Martikainen and Valkonen 1998). Younger widows and widowers exhibited increased psychopathy compared to those in the older age groups (Zisook and Schacter 1991).

Comparing 242 widows and 76 widowers, Kaunonen et al (2000), in their Finnish study, felt 26% of widows and widowers worried how to survive. 18% of widows worried about illness and death compared to 10% of widowers. Loneliness was felt by 17% of widows and 26% of widowers, and the loss of their relationship and the life they would have had with the deceased worried 12% of widows and 9% of widowers. Statistically, the only difference reported was the increased incidence of panic behaviour felt by widows, especially related to performing new tasks such as managing their financial affairs. Zisook and Schacter (1991) report similar findings, reporting that widows demonstrated more anxiety than the widowers, with the nature of the marital relationship not a significant factor.

Exploring the nature of the marital relationship, a Canadian study of widows and widowers, reported that secure attached individuals were less angry, less socially isolated, less guilty, had less death anxiety, less somatic symptoms, less despair, less depersonalisation and ruminating. Secure individuals reminisced about the deceased more than insecure people. The authors concluded that attachment style had an effect on spousal grief. Bonanno et al (2002) suggested that the clearest predictor of grief was excessive dependency on the relationship. However, no significant differences were found with conflict and ambivalence towards the spouse in most of the groups in their study. Although, the chronically depressed group in the study were reported as being less positive about their spouse and marriage. A study by Field et al (2003) found that the greater the continuing bonds were after the death of a spouse, the greater the severity of the grief. When a greater satisfaction was reported by the participants about the relationship

prior to the death, the authors concluded that it was predictive of a higher continuing bond with the deceased. Some of the continuing bonds remained long after the death.

Hyrkas et al (1997) in a study of Finnish widows and widowers suggested that widowers who had lost their spouse more than two years previously, displayed feelings of blame and anger, more than the widows. There was no significant difference, however, between the two genders for those who lost their spouse less than two years prior to the study. Manor and Eisenbach (2003) also found no differences between the genders in their longitudinal mortality study in Israel.

When considering suffering, Zisook and Schacter (1991) found that most of the widows and widowers had a depressive episode at some time during the seven months after their bereavement and that this episode did not begin until some time after the first months of bereavement. A quarter of their sample met the DSM-III category for clinical depression. Bonanno et al (2004) found nearly half of their sample showed little or no depressive symptoms and that 10% actually had an improvement in their mental health following their loss, the remainder showed low levels of depression even before the bereavement. Therefore it appears before diagnosing chronic (complicated) grief after spousal loss, it is important to first define the difference between chronic (complicated) grief and chronic depression, which may have commenced before the bereavement (Bonanno et al 2002).

Bonanno et al (2002) also found, in their prospective longitudinal study of widowers and widows that most of the sample (90%) were captured into five conceptually relevant patterns: common grief (11%), chronic grief (16%), resilient (46%), chronic depression (8 %) and depressed-improved (10%). Overall, the most frequent bereavement pattern was the low depression resilient pattern. Each group reported at least some grief symptoms at 6 months post-loss, which demonstrated a decline with time; however the resilient individuals had fewer grief symptoms than all the other groups except for the depressed-improved. By 18 month post-loss the resilient,

common and depressed-improved groups did not differ from each other. However, the chronic depressed and chronic grievers (who did not differ significantly from each other) had greater grief than all the other groups. One of the clearest predictors of chronic (complicated) grief was the excessive dependency both on spouse and general personality variable. Although those with chronic (complicated) grief presented as one of the smallest groups, Bonanno et al (2002) felt they were the most of need of intervention.

Following on from Bonanno et al's (2002) theme that the greater the dependency of the relationship, the greater the incidence of chronic grief behaviour, Field et al (2003) add that the greater the continuing bonds the widow or widower had with the deceased after death, the greater the chronic grief pattern. Unfortunately, Field et al (2003) do not explore the influence of gender on their findings. If the widow or widower felt more securely attached to the spouse prior to death, Waskowic and Chartier (2003) reported that they subsequently were less angry, felt less socially isolated and less guilty, had less death anxiety, presented with less somatic symptoms, less despair, less depersonalization and ruminating. Secure people reminisced more about the deceased than insecure people and it was felt that attachment style had an effect on the participant's grief.

A widow's ability to cognitively adapt and demonstrate an optimistic positive manner was thought by O'Rourke (2004) to be related to an increase in life satisfaction and facilitate a reduction of psychiatric distress. Yet O'Rourke (2004) adds that the relationship between personality and positive well-being was an indirect one and that cognitive adaptability was a greater positive indicator of adjustment in widowhood. The Nolen-Hoeksema et al (1997) study of gay widowers reported that the men who evidenced more negative ruminative thoughts showed greater psychological distress. Men who engaged in increased analysis of themselves and the meaning of their loss, reported greater positive morale at 1 month after the loss, however this was counterbalanced with more persistent depression and absence of positive

state of mind over the 12 months since their loss. Social friction on the other hand evidenced enduring depressive symptoms.

Social support throughout most of the studies appeared to be the most important source of support, especially from family and friends (Duke 1998). Having to re-align assumptions about self, relationships and life which no longer fitted to their current reality (Danforth and Glass 2001) was also an important process of being widowed which initially could bring feelings of stigmatisation (Lieberman and Yalom 1992).

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Spousal loss		
Systematic or systematic type review		
Literature or literature type review		
Experimental/RCT	Lieberman and Yalom (1992)	1
Case Control/Cohort	Avis et al (1991)	1
Observational (no comparison group)	Bauer and Bonanno (2001), Bonanno et al (2002), Bonanno et al (2004), Field et al (2003), Hyrkas et al (1997), Kaunonen et al (2000), Manor and Eisenbach (2003), Martikainen and Valkonen (1998), Nolan-Hoeksema et al (1997), O'Rourke (2004), Powers et al (1994), Waskowic and Chartier (2003), Zisook and Shucter (1991)	13
Mixed methods		
Qualitative	Danforth and Glass (2001), Duke (1997)	2
Opinion/text		
Books, Book Chptrs	Stroebe et al (2001)	1
TOTAL		18

Key messages in Spousal Bereavement

Attention should be paid to the whole family in the bereavement process, with consideration by bereavement and support agencies in how to facilitate family and friends as mechanisms for social support to the bereaved.

Support services should observe that symptoms of grief are reported by families to decrease over time, although can present intensely immediately after the death of a spouse.

Practitioners should be aware of how important reminiscing is to widows and widowers. Less secure individuals tend to reminisce less.

Services should provide a primary preventative focus of care for high-risk and high-distress individuals, using a systematic assessment that identifies high risk factors.

Education is suggested for the bereaved and their potential support providers incorporating the diverse forms that grief may take.

Chapter 7: Older People

A number of aspects become apparent when looking at the literature surrounding older people. There is not really a consensus on what constitutes old age (ages ranged from 50 to over 80 in the studies examined). Similarly the boundaries are becoming increasingly blurred as to what constitutes care (and where it is given). This is not helped by fragmentary research, which does not collect a wide enough range of experiences from which to draw good practice. Much of the work is theoretical or negative, highlighting a lack of care. Two areas of focus that dominate the research are spousal loss and grief.

The literature discusses the concept of residence and what constitutes a home. Gott et al (2004) examines concepts of what a home is from the perspective of older people. Whilst older people see the 'home' as an essential part of a good death it is possible that later in the dying trajectory they would prefer to be cared for in a different place. Indeed, Bond et al (2003) suggest that the yielding of care of individuals with dementia and their subsequent death has a positive effect on the bereaved in relation to their health status, psychological well being and activity participation, which would suggest that for some elderly the relinquishment to care establishments may be a positive intervention for those bereaved. In addition, Ryan (1992) found a comparatively reduced death rate in those who had their loved ones admitted to care establishments, suggesting that relinquishing of care can be a positive event. Bass and Bowman (1990) agree that by targeting interventions prior to admission then the support of the bereaved is greatly increased.

Death in institutions can be described as not homely, because family members are cared for by professional strangers. This apparently creates fewer burdens on family but also reinforces the idea that 'proper care' cannot be provided at home. To counteract this, workers may adopt the metaphor of family so that 'caregiving becomes more meaningful when professional

distance is weakened and residents are humanized', Moss et al (2003), p 293.

Bass and Bowman (1990) suggest that the greater the care-giving strain on an individual prior to bereavement then the greater the strain on the individual post bereavement. To counter this they suggest that interventions should commence pre-death to relieve the burden of care and that relinquishment of care to care homes is not the only option. By entering into a partnership with the carer to maintain the dying individual at home perhaps the suggestion of care in the home as being 'improper' as suggested by Moss et al (2003) can be addressed.

Cotter et al (2004) also examine life within care institutions and find that much of the research is fragmentary in that it looks from a single perspective or methodology, which in fact hides aspects of other people's loss within these institutions. Current research results in an incomplete picture being presented. Having examined a wide variety of research they find that often there are divisions within the literature which result in only partial analysis of larger experiences.

In one of a number of papers and chapters (See: Katz et al 2000 also Komaromy 2000, Katz and Peace 2003 and Katz et al 2001) which explore an earlier report, Katz et al (2000) examine palliative care provision within a handful of English care homes. This mixed method study finds that homes do not have uniform policies for dealing with bereavement, or in fact for supporting dying residents. A lack of support for bereaved families and staff may be exacerbated by the fact that often staff do not have the necessary skills or training to be able to implement proper support.

Within practicing aged care physicians, surveyed by Boyatiz et al (2003), lack of skills was not seen as an issue however the participants did admit to having inadequate preparation for dealing with the bereaved. They did not recognise, however, that they should provide such support to the bereaved, as the deceased's physician. Rather they supported the idea that there

should be a bereavement service provided using hospital and community based resources.

The concept of concealment discussed by Katz et al (2000) argues that the concealment of the body in terms of sight is done as a ritualized performance where the focus is on the dead body. There is no concealment of sound, as most of the emphasis is placed on the focus of seeing and confronting death; something that staff try to keep from other patients and residents. However for all the distancing that occurs as a method of protecting staff, there can be closeness with patients and residents in care. The paradox of treating residents as kin is explored more fully in Moss et al (2003).

Often an over-acceptance of the medical model has caused concern. Within the ward structure there is a delineation of roles when patients are dying, nurses often focusing on physical pain (Costello 2001). Whilst Costello (2001) recognises the need to tend to the spiritual and emotional aspects of care, there is little evidence that this is implemented, which is in keeping with the findings of Cotter et al (2004), and also the grey literature which provides scant mention of spirituality and emotion. Similarly the lack of proper disclosure means that there are concerns of truthfulness and a lack of meaningful engagement with patients who are dying (Komaromy, 2000). This can result in a lack of congruity between actual care and discussed or planned care.

In order to address the emotional aspects of care of the bereaved several suggestions have been made. Tudiver et al (1995) identifies that emotional support through regular support group meetings and incorporating health promotion fills many of the bereaved individual's needs; whilst Segal et al (2001) suggests that by encouraging the venting of emotions then distress post bereavement is greatly decreased. This venting of emotions helps to re-focus on the positive aspects of the lost relationship which also helps promote adaptation. Ong et al (2004) and Bisconti et al (2004) both identify that by keeping a daily diary focusing on emotional wellbeing then the bereaved can find equilibrium. They suggest that emotional vacillation is

normal and we should expect this. Once this is accepted then the bereaved can be supported further by allowing them to own their feelings.

A methodological concern arising from the literature, however, is the point of assessment of emotional needs of the bereaved elderly. Much of the research takes an initial assessment close to the point of bereavement. Lichtenstein et al (1996) suggest that this may be a major flaw in the research to date. In their longitudinal study, they found that there was a substantial increase in depressive symptoms over several years in the bereaved when the dying has suffered chronic illness. They suggest this is an anticipation effect and the research which suggests that 'normal' is reached within two years of the death may be seriously flawed.

Within the context of the medical model, the diagnosis of terminal illness may be seen as important, as it may have a profound effect on attitudes towards older people where death and dying become seen as part of old age (Parkes 1997). The fact that there is no cure for the illness means that the management of death is seen as an act of failure in terms of medicine, rather than a well rehearsed microcosm of pain free living.

Clearly the definition of old age alone raises qualitative issues, see for example the International Work Group on Death, Dying and Bereavement (2000). By the fact that the elderly are classified as a singular homogenous group confirms the 'ageist myth' for the above writers. There is diversity within this group of older people that is often overlooked, a point that needs to be addressed in future research. They also offer a range of inaccurate myths which need to be addressed.

Fortner and Neimeyer (1999) in their systematic review of the literature in the elderly found similar themes in the literature. There was a distinct lack of homogeneity in the studies explored in the elderly whether in instrumentation, definitions used, age sample, social context and design, however Fortner and Neimeyer (1999) raised some important issues including that bereaved individuals in institutions have greater death anxiety, which suggests that they need more support; in addition, gender and

religiosity is not a factor in the anxiety they feel. However, gender has also been highlighted in several other studies discussed in this review (Bennett 1998, Fitzpatrick 1998).

Fitzpatrick (1998) focuses on gender issues in bereavement and examines men's reactions to death and dying, in terms of the effects on stress and health arguing that health is affected by stressful life events and men are more likely to encounter higher rates of psychological and physical disorders as a result. These ideas which are supported by Bowling (1994), Byrne & Raphael (1997), Bennett (1998) and Li (1995), who all found greater incidence of mental health decline, depression and risk of suicide ideation in older males. For men the death of a parent, child or other close relation is likely to be felt in a similar way to the death of a spouse. What seems to be clear is that the processes of bereavement may be different for men from those for women, in that men are more susceptible, however, Bennett (1998) points out that the depression in males may be linked to the change to singlehood and the adaptation that this creates as much as the bereavement. It is clearly the case that for older people loneliness is a major factor in their grieving process.

Much research deals with an older population which is under 75 years. In fact mean scores can be considerably less (Harwood 2001). Possibly another way to differentiate the differing needs of older people is to adopt the approach by Hegge and Fischer (2000), who separate the 60 plus age group into two: the 'young old', or seniors (60-74 years), and the 'old old', or elderly (75-90 years). From their research they found that there are differences between these groups in terms of grief. Seniors may still have an effective social support network in place in the community, being able to draw upon family in the first instance and then friends later. However, older people are more likely to have witnessed the institutional death of a loved one, which could hasten grief, in addition to experiencing anticipatory grief prior to death. Hegge and Fischer (2000) also reflect on the range of multiple losses likely to be experienced within these groups.

This age difference becomes apparent in much of the research with differences in grief reactions being explained through age. Xavier et al (2002) in their study of over 80s found that the presence of grief in this age group was not associated with depression or generalized anxiety as is commonly believed but it was however, linked with age related cognitive decline. Lalive d'Épinay et al (2003) agreed that there was no link in this aged group between grief and depression; moreover they found no links between grief and health either physical, functional or emotional. Whilst Lichtenstein et al found that widows over the age of 80 years had the best psychological health of widows. This implies that the impact of grief on the 'old' old is not as significant a factor as expected. This lack of a link with depression in the 'old' old however, is contradicted by Turvey et al (1999) who found higher rates of depression in the older subjects, and in the newly bereaved found depression to be up to 9 times higher than non-bereaved individuals. Schulz et al (2001) suggest that the depression is linked with the strain of care giving prior to death. However, with much of the research there is no consistency in groups, methods of assessment and variables. As a consequence many of the findings in this area are contradictory.

Spousal loss in older people

The following quote summarizes a mood within research, as it tries to reclaim death dying and bereavement issues;

'We believe that clinical lore which medicalises grief projects a somewhat distorted picture, especially in that it is underpinned by an analogy to physical trauma from which the successful and expected outcome is "full recovery". If a medical analogy is to apply, then we suggest that metaphors of "wounds", "blows", or disease should be replaced by that of amputation. Not only does that fit many peoples subjective imagery...but it also makes clear that a loss is a loss and it is permanent, however well adapted to or compensated for'. Bennett and Bennett (2001), p248.

The focus here is on spousal loss, where a partnership ends after one or other dies. The description of loss being permanent, where someone loses part of themselves is possibly most pertinent in the area of spousal loss, which makes up a large body of literature in the area of older people and bereavement.

Where older people have a monopoly over death can mean that bereavement becomes an issue for spouses and partners. Where women outlive men, bereavement can also be seen as a gendered issue Parkes (1997). Death also affects the family as a unit (and as individuals) in different ways ; as Abeles et al (2004) points out children of a parent who has died are likely to be mature adults, possibly with families of their own.

Kivela et al (1998) in their study looked at the loss of a parent in youth and its impact on old age. They found that the loss of a mother in males under 20 and the loss of a father in females under 20 may be a predictor of depression in old age. They suggest that this loss may make the bereaved psychologically vulnerable to traumatic life events or stressful life situations and that loss in later life can re-activate this trauma. However, it should be

noted that the number of subjects included in the depressed elderly group was low overall. The results, however, suggest that bereavement of the young has long reaching influence on the mental health of those individuals much later in their lives.

There is a need for greater awareness of issues arising from the affects of death on differing age groups Abeles et al (2004) which are not always generalisable, Bennett and Bennett (2001).

Abeles et al (2004) highlights a number of treatment options and interventions that may be useful, but admits that these may only be necessary for a much 'smaller proportion of bereaved individuals', p236. Utilizing a range of interventions which incorporate and include the family may prove to be useful and whilst certain 'tasks' may need to be incorporated into therapy or intervention, these will be unique in many cases to the individual. Raising awareness that the bereaved do not follow the predestined stages comes alongside recognizing the autonomy of adults, to break free from parental bonds of attachment. The elderly mourner does not need to emotionally disengage, bonds continue (Costello and Kendrick 2000).

Several randomized studies also suggest the use of antidepressants in the elderly (Reynolds et al 1999; Oakley et al 2002). They suggest that normal antidepressant therapy has good effect. Whether this would be different in a young age group is not explored. Boerner et al (2005), however, suggest that antidepressants should only be considered after a period of adaptation. They suggest that differing expressions of grief are not necessarily a point of concern; rather they are part of what makes us each individual and grief, whether expressed or not, should not be viewed as abnormal. Frank et al (1997) in a review of the literature and introduction of a trial with support groups found that encouraging the retelling of the death story over a prolonged time period was useful as a therapy. They also suggest that structured re-visits to important events and places helps with adaptation.

Caserta and Lund (1993), however, indicate that although self help groups can be an aid for the older bereaved spouses who do not have other

resources such as friends and family and high self esteem, it is better to help them to focus on how to use their own strengths effectively. Self help groups, they argue, can be distracting to those who have good personal support resources.

Costello and Kendrick (2000) suggest that “‘Dwelling on the past”, at least initially, is a natural response to loss’ (p1379). This is the basis of reminiscence as a valid approach, whereby widows and widowers can dwell on the past, at the start of bereavement, as a way of working through a series of emotions which are often painful and negative. They highlight three main themes: feelings of isolation, a sense of loneliness and depression, and inner representation and dialogue with the dead.

Research consistently highlights that bereavement takes time and many people are still feeling the after effects years after the death of a partner. During the first six months community nursing can be provided, according to Lytle (2001), but research shows that most nursing interventions do not last that long.

Evidence highlights that widows often develop stories or narratives about the events leading up to the death of their partners. This involves three processes:

- committing the story to memory
- continuing the bond with the deceased
- public presentation of the story.

Continuing the bond with the dead is therefore achieved through the action of rehearsal and performance and these become important. Many older people look for opportunities to develop these naturally occurring narratives (Bennett and Hall 2000).

Grief in older people

Costello (1999) argues that grief involves older people making adjustments to their lives and that loneliness can be separated out from grief in bereavement. He also recognizes that many older people are not undergoing a singular loss but in fact multiple losses, (also raised by Parkes, 1997), where each loss possibly impinges on the previous loss(es). In some ways this makes bereavement for older people more complicated as they have to cope with social sequestration, ageist myths and a 'series of life transitions when grief occurs'.

In real terms helping an individual to realize that they are normal and accepting this may be the role of therapeutic intervention, counselling and support services. Loneliness may occur as a result of grief, but supporting the person to see both the normality of their situation, and also the wider social context, may develop better connectivity and reduce sequestration of older people.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Older People		
Systematic or systematic type review		
Literature or literature type review	Cotter et al (2004), Fasey (1990), Fitzpatrick (1998), Fortner and Neimeyer (1999), Frank et al (1997), Harwood (2001), Parkes (1997)	7
Experimental/RCT	Oakley et al (2002), Reynolds et al (1999), Segal et al (2001), Tudiver et al (1995)	4
Case Control/ Cohort	Bisconti et al (2004), Bennet (1998), Byrne and Raphael (1997), Lalive d'Epinay et al (2003), Li (1995), Ong et al (2004), Schulz et al (2001), Turvey (1999)	8
Observational (no comparison group)	Bass and Bowman (1990), Bennett and Bennett (2001), Bond et al (2003), Bowling (1994), Boyatzi et al (2003), Caserta and Lund (2003), Kivela et al (1998), Ryan (1992), Xavier et al (2002)	9
Mixed methods	Katz et al (2000), Katz et al (2001), Komaromy (2000)	3
Qualitative	Bennett and Hall (2000), Costello (1999), Costello (2001), Costello and Kendrick (2000), Gott et al (2004), Hegge and Fisher (2000), Lyttle (2001), Moss et al (2003)	8
Opinion/text	Abeles et al (2004), International Work Group on Death, Dying and Bereavement (2000)	2
Books, Book Chapters, Reports etc	Katz and Peace (2003)	1
TOTAL		42

Key messages in Older People

Boundaries of care are becoming blurred as older people stay at home longer.

Research needs to reflect the range of loss for example more work on range of experiences, (throughout the age group) and the effects of multiple losses.

There is emphasis on the place for reminiscence in the therapeutic care of elderly people. There is a need for commissioned workers, with a specific remit to explore and reminisce with older people in a similar way to counsellors or other therapists.

Most clearly there is a need for enhanced training and broader understanding of grief especially with older people.

More clear delineation as to what is meant by the term elderly.

Consideration of gender and structure interventions to address the differing needs of the elderly population, particularly issues such as loneliness.

Chapter 8: Spiritual/Cultural aspects of Bereavement

The theme related to spiritual and cultural aspects of bereavement covers material that is focused on spirituality, including religion and the cultures in which these occur. There is, across the majority of themes in this review, literature related to culture. However, there was a range of material (mostly text and opinion) that explored the spiritual and cultural dimension of death and bereavement and which we considered related specifically to health and social care. It was therefore decided to provide an overview and synopsis, particularly as the SEHD had published guidance on Chaplaincy and Spiritual Care in NHSScotland (NHS HDL 76 2002) based on a report from the Working Group on Spiritual Care in the NHS (McGregor 2002). The guidance instructed NHS Boards to develop and implement a spiritual care policy. In conjunction with this SEHD had also produced guidance on culturally-competent services (NHS HDL 51 2002).

The spiritual care guidance affirms the need to develop policy and practice in this area through establishment of relevant structures and processes within each NHS Board. The term 'Spiritual' is viewed as a more appropriate term to cover the 'work'. However, the guidance highlights the problem of a lack of information on people's spiritual affiliations (and needs) and also the difficulty of quantifying the amount of time that is devoted to spiritual care and how it is being carried out. What appears important is having an appropriate range of religious and spiritual personnel involved to support patients, their families and staff (Marrone 1999; Lomas 2004). Lomas (2004) also indicates that such departments should offer staff the opportunity to 'offload', which suggests a counselling function.

One of the key differences across all religions and cultures is the private versus public event of death and mourning. As Parkes, Laugani and Young (1997), identify in some cultures, death and mourning is a social affair, in others such as in Northern Europe and the US it is a private restrained affair. They indicate that there is 'no evidence' that one approach is better than

another in terms of impact on the bereaved. However, they are clear (Laugani and Young 1997) that we should be aware that there are considerable intra cultural differences that exist and there is a need to avoid stereotyping.

According to Laugani and Young (1997) the loss of 'traditional religions' and the increased secularisation of society has resulted in many rituals and responses to death and bereavement being no longer available. The consequence is that services, such as those provided by bereavement counsellors, now provide a crucial role in provision of human comfort, facilitation of mourning and reducing traumatic grief. Walter (1996) identifies this move to individual focused spirituality in bereavement care being fostered by the hospice and palliative care movements. Individualisation of faith means the person is the authority, beyond religion and medicine, and their self awareness and search for meaning is what is important (Doka 2002). How nurses are able to provide care in such circumstances is questioned by Walter (1996) as few know what is meant by the spirit. However, this move to secularity is mirrored in the move to develop and offer a broader and better level and range of spiritual care throughout NHS Scotland (HDL 76 2002). This guidance also highlights the need for those who directly care for patients and their families to have skills, which demand professional development education and training. It does not identify issues related to spiritual care in pre registration/ undergraduate curricula.

What rituals and practices are available may be considered as helpful in assisting those who have a loss to grieve (Doka 2002). Stroebe (2004) however, in reviewing the evidence on religious variables (including beliefs), concludes that the evidence is uncertain and cannot be accepted as showing that beliefs (religious) influence outcomes in bereavement. This is not to suggest that for many, with such beliefs, these are not helpful but merely to highlight the difficulties surrounding research into this area where definitions, specifications and confounding variables are not concise or considered. Austin and Jennings (1993) is an example of the problems in determining

definitions and specifications and the lack of control over confounding variables. However, the study by Walsh et al (2002) seeks to address some of these problems and identifies spiritual (not just religious) belief as an important factor in assisting grief and that it may be more useful in identifying those who are having difficulty readjusting to life after loss. It may be that such a dimension fits approaches such as the logotherapy of Victor Frankl, that is a search for meaning and purpose (Walter, 1996) and may be better termed existential, rather than spiritual.

The way in which chaplains engage with death, dying and bereavement and the amount of involvement is relatively unknown. Gordon (2004) highlights the potential for Christian clergy to utilise the continuing bonds model of grief (Klass, Silverman and Nickman 1996) in conjunction with theology as an aid to facilitate grief and bereavement. Attending to religious or spiritual beliefs in psychotherapy may be problematic and viewed as creating conflict between the therapist and client (Golsworthy and Coyle 2001). However, Azhar and Varma (1995) indicate that for those with religious faith (Muslim) religious psychotherapy may result in better outcomes and less reported symptoms of depression. However, Marrone's (1999) review of spirituality in death, dying and bereavement concludes that what is important is that the ways in which meaning is 'rediscovered' is less important than the process itself. A finding echoed in cancer patients by Murray and Grant (Research Matters, CSO website) and by Golsworthy and Coyle (1999) who also conclude that spiritual aspects are an inherent part of other forms of support, other than psychotherapy.

The practical matters related to death are of course important and all of the NHS board policies/protocols/procedures reviewed contain some element of direct description of what to do after death, including in relation to the religion of the deceased. This is also found, for example, in procedure manuals such as that produced by the Joanna Briggs Institute.⁹ Nurses,

⁹ <http://www.joannabriggs.edu.au>

according to Quested and Rudge (2003), are obliged to care for the body of a dead patient in a manner reflective of the values and culture of the institution, no one else undertakes this. As has been described in other parts of this review the inclusion of relatives and family into this procedure can be helpful. It may be considered that this ritual is one way of delineating the move of the person from life to death.

Funerals, like last offices, also facilitate the transition from life to death and provide an opportunity for public displays of grief (Romanoff and Terenzio 1998). However, there is a perceived lack of ongoing ritual in secular western countries to assist the bereaved, despite an acknowledgement that they can be useful. They may play a role in allowing the bereaved to move on but in a transformed way which may also maintain connection to the deceased rather than an absolute 'letting go'.

Stroebe and Schut (1998) highlight a variety of different cultural variations in 'normal' grief. They suggest that their dual process model of coping with loss can fit to different cultural contexts. The model identifies the experience of bereavement as oscillating between loss orientation where the person is engaged in grieving and restoration orientated where the person is adjusting to life in the changed world and avoiding grief. The degree to which oscillation occurs will be determined by many factors including cultural and spiritual. Irrespective of model of grief, Parkes (2000a) argues that there are some universal components of grief that are common and related to the psychological attachments of the individual. However, in addition to this universal core it must also be acknowledged that bereavement will be shaped by cultural context (Catlin 2001).

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Spiritual/Cultural		
Systematic Review		
Literature Review	Marrone (1999)	1
Experimental/RCT		
Case Control/Cohort	Azhar and Varma (1995), Walsh et al (2002)	2
Observational (no comparison group)	Austin and Jennings (1993), Catlin (2001)	2
Mixed methods		
Qualitative	Golsworthy and Coyle (2001), Murray and Grant (CSO website), Quested and Rudge (2003)	3
Opinion/text	Doka (2002), Gordon (2004), International Work Group on Death, Dying and Bereavement (1990), Lomas et al (2004), McGregor (2002), Parkes (2000a), Romanoff and Terenzio (1998), Stroebe M (2004), Stroebe and Schut (1998), Walter (1996)	10
Books, Book Chapters, Reports etc	NHS, HDL 76 (2002), NHS HDL 51 (2002), Parkes, Laugani and Young (1997), Klass, Silverman and Nickman (1996)	4
TOTAL		22

Key Messages in Spiritual/Cultural aspects of Bereavement

Need to develop programmes of education for spiritual care that also consider the extent to which spiritual care is part of any health professionals pre-registration/undergraduate curriculum.

Spiritual and culturally competent care should be an integral part of care within health and social care environments.

Having a range of professionals and volunteers who can support spiritual care is important and they should contribute to teaching and development. Consideration needs to be given to the extent to which this service might also provide counselling support to staff.

Normal grief may vary between cultures and awareness of cultural difference should be part of local guidance.

SECTION THREE: Specific Areas of Risk/Challenge

This third, shorter, section deals with a range of factors that were identified as of particular significance in the literature. These were specific enough to warrant appraisal and extraction in their own right and the key messages could be seen to cut across areas of the life span presented in the previous section. Chapter 9 deals with death that occurs through trauma and the subsequent consequences for bereavement, this is particularly pertinent considering the potential for post traumatic stress disorder to occur. Chapter 10 covers bereavement issues that have arisen more recently with the advent of HIV/AIDS. However, the predominance of literature in this area is Western in orientation and does not engage with the significant death and bereavement issues in, for example Africa. The final chapter in this section (11) reviews the small but significant area of bereavement related to learning disability. Its inclusion was due to an identified clear area of concern that we believed illuminated a neglected area related to bereavement.

Chapter 9: Traumatic Deaths

This section takes into account that particular types of death and circumstances surrounding the death, may affect the process of grieving and consequently have implications for the care and support required for individuals and communities. For ease of reviewing some of the literature the area was divided up into trauma, disaster, murder and suicide. Some of these areas inevitably overlap, as they do with other sections in this review.

Trauma

One of the issues arising in the literature in this field concerns the way that historically and conceptually trauma and bereavement research have taken different routes. In early work on grief the area of trauma was not considered though different terms have been used to mean the same thing; traumatic, complicated, and pathological (Stroebe et al 2001; Rubin et al 2003). Stroebe et al put forward a diagrammatic representation of the 'interface' between trauma and bereavement and describes their common themes. Common aspects of trauma and bereavement include: the type of event, impact of intensity, psychological reactions including disorder and assessment. Rubin et al (2003) argue for a 'multi-channel' approach to the phenomena of trauma interfacing with bereavement, which they call 'The Two Track Model'. They argue for an inclusive vision of bereavement and trauma which features the individual interpretation of life experiences within the process. This acknowledges the possibility that a stressor or bereavement may be subjectively experienced as traumatic whilst not objectively being perceived as such. Stroebe et al (2001) are of the opinion that more research is needed to document whether or not pathological grief differs from reactions to trauma such as Post Traumatic Stress Disorder (PTSD) or 'normal' reactions to bereavement. They state that they would guard against pathologising grief further by creating additional categories of mental illness. Chapter 3, *Complicated Grief*, provides a more full discussion of this topic and specifically the more recent work of Holly Prigerson and colleagues.

There is some suggestion that bereavement subsequent to violent death is associated with higher levels and more enduring distress (PTSD symptoms), than bereavement under natural circumstances (Kaltman and Bonanno 2003). In this study the authors examined the relationship between PTSD and depression in a sample of middle-aged spousally bereaved adults. Initially, the group bereaved through violent means exhibited more PTSD symptoms than those who had lost a spouse due to natural causes, which diminished over time. However, the sample was small and recruited via advertising. Participants were also paid for their involvement, a feature of several American studies in other chapters of this review.

Bereavement as a result of road traffic accidents (RTAs) is examined by Stewart (1999) in the USA and Tehrani (2004) in the UK. Stewart (1999) suggests the act of informing survivors of the death of their relative in an RTA should be seen as an opportunity by the health care professionals as an opportunity to influence the course of bereavement. The paper offers a framework for doing this. Tehrani (2004) examined data collected over an eight year period from injured and bereaved victims of RTAs who had contacted RoadPeace (a national charity for road traffic victims). A wide range in the level of care and support provided was identified. The authors encourage the creation of a national programme of support that provides early assistance and information followed by support to promote self management.

In terms of individual characteristics which influence people's ability to cope with loss and trauma, George Bonanno (whose work is encountered elsewhere in this review) features as a key researcher in the field of 'human resilience'. He believes that resilience is a dimension of human experience within the field of loss and trauma that has been underestimated in the past (Bonanno 2004). Resilience is described as a phenomenon which is different from recovery and is commonly present in individuals and may explain why people continue to function and have positive emotional experiences following traumatic loss. There are thought to be several elements which can contribute to resilience

including hardiness, self-enhancement, repressive coping, positive emotion and laughter.

There are various perspectives concerning which approach is best to assist people following traumatic bereavements. In Chapter 12, *Interventions*, evidence is appraised that suggests people with more complicated and prolonged grief reactions benefit most from interventions. From a psychotherapeutic view Rubin et al (2003) describe therapy for traumatic bereavement as reworking the individuals relationship with the deceased. From a sociological standpoint Dyregrov (2004) is of the view that families experiencing traumatic bereavement may not have the same access to services as people with physical illnesses. Dyregrov (2004) suggests families may feel disempowered when they do not have appropriate choice in access to services. Her work was based in Norway on a large study with families who had lost a child. She uncovered the themes of 'social ineptitude' (pp31-33) and 'survivors openness' (p34). The former related to the communities inability to respond to the parents grief and withdrawing, and the latter to the positive influence of families being able to tell their story of loss.

Disasters

Bereavement following disasters is a complex area, given the variety of natural and man made disasters that can arise, the different phases and the different approaches to help in each phase (International Work Group on Death, Dying and Bereavement 2002). By definition, disasters involve large numbers of people and require different responses and levels of intervention. Norris et al (2002a/b) reviewed the disaster literature from 1981-2001 and chose to divide the research into types of disasters and then categorise as to the type of psychosocial outcomes. Their review included 160 research articles and 250 chapters in books. Bereavement is mentioned as one aspect of disasters that can affect mental and physical health of survivors and those who are most at risk of long term effects can be identified early in the aftermath of disasters. Norris et al (2002b) call for more research into 'system level factors' and the way in which agencies can respond to help in the early stages. Although not formally

reviewed here, it must be worth considering how health services' disaster plans incorporate bereavement support.

Taking a psychotherapeutic approach Reyes and Elhai (2004), feel that training in treating trauma-related disorders is not sufficient preparation for conducting psychosocial disaster intervention. They add to the view that early interventions may not be helpful and that emotional reactions may take several weeks to show. Reimers (2003) describes the social and community responses to the sinking of the Estonia in Sweden, and the process whereby it was eventually decided to leave the bodies of the passengers inside the ferry in the sea. She used newspaper articles in her discourse of describing how the ship moved from being an accident site to a graveyard. She described this as reaffirming 'a notion of grief as sentiments that move from irrational shock to rational acceptance in which rites and rituals play a significant part' (Reimers 2003, p.338).

Murder

The Violence and Grief Work Group (1998) examined the relationship of violence and its aftermath to bereavement and developed principles which they felt should guide a community response. Some of these principles are relevant to bereavement following murder. The reactions to violent death would be influenced by factors such as the nature and circumstances of the death, physical and mental trauma to the survivors, identification with the perpetrator, and the nature of the relationship between the survivor and the deceased. The group acknowledge the beneficial support that can be provided by appropriately selected and trained individuals. Hatton (2003) in a survey of homicide bereavement counselling found that counsellors (voluntary and professional) who had been bereaved themselves through murder may be more aware of the needs of those bereaved through murder. In this survey survivors valued self help provision more than non-survivors. Parkes (1993), through a series of case studies, describes 'self-perpetuating vicious circles' that people may display following bereavement by murder or manslaughter, fitting the diagnostic criteria of PTSD, which require therapeutic interventions.

In the case of parents grieving the loss of a child through murder, particular problems may arise (Riches and Dawson 1998). Riches and Dawson interviewed parents following the death of a child, producing a compelling account of the processes following murder which had a profound impact on the parents' grieving. This included the management of the death by the police and coroners office which prevented the parents having control over aspects such as seeing and touching their dead child, and planning the funeral. In some cases parents had been interviewed as murder suspects.

Accounts of people's reactions after traumatic forms of bereavement vary as to what may help most. Some evidence is anecdotal, though powerful nevertheless, such as a short account of parents' experiences of a support group formed following the Dunblane killings of primary school children (Frean 1998). One mother's comment was, 'I look forward to Thursday to go and have a blether with the girls, where we can have a drink, a laugh and are not crying all the time' (p.26).

In such situations people are not only dealing with their own emotions but those of the community, including media attention. This is equally the case after terrorist attacks, for example in New York on September 11th 2001. However, although not all people will require special attention, a minority may go on to experience symptoms of PTSD (Parkes 2001).

Suicide

The studies reviewed in the field of suicide and bereavement come from a variety of perspectives using different methods. Few conclusions can be drawn as to how people can be helped best following the suicide of someone close from the evidence presented. In particular there are problems with small sample sizes and self selected groups under investigation.

There is some recognition that bereavement following suicide may provoke reactions that warrant special consideration and attention (Bailey et al 1999, Jordan 2001). In addition to survivors experiencing the usual grief reactions, including anger, guilt, blame and asking 'why?', there are factors which may lead to grief becoming complicated (Mitchell et al

2004). The reasons for this are thought to be varied. People who commit suicide are more likely to be young and to have had previous problems and conflict in relationships (Clark 2001). Families left behind are more likely to feel a sense of stigma, shame and rejection (Bailey et al 1999, Harwood et al 2002). The actual circumstances of the death and the legal process may create further distress for those left behind. Inquest procedures and reporting of suicide deaths from the coroner's office may add to this distress. Those who are grieving following suicide are also at greater risk of contemplating suicide themselves (Jordan 2001).

When considering support for people bereaved by suicide a cultural and social perspective is seen as vital (Pietila 2002). Support from family and friends has been shown in some studies to be the most protective factor in bereavement (Callahan 2000, Barlow and Coleman 2003). Provini et al (2000) reported that bereaved next of kin would have liked some kind of 'professional therapy', although the help most likely received was from family, friends and the community. Barlow and Morrison (2002) reviewed the range of counselling strategies available including cognitive, affective, solution-focused and psycho-educational strategies, without being able to conclude which may be the most helpful.

Family therapy is another therapeutic approach which Kaslow and Aronson (2004) believe can move families on to create their 'story' of what has happened. The inner world of those bereaved by suicide is explored qualitatively by Fielden (2003) in an attempt to understand how family members deal with their grief. In Belgium the fact that within the Flemish region suicide is the leading cause of death in the 15-25 year old age group has prompted a national programme to increase bereavement support. The working group involved includes representatives from mental health institutions, social programmes and suicide survivor groups (De Fauw and Andriessen 2003).

In Scotland there are approximately 600 suicides each year. The national strategy and action plan, 'Choose Life', introduced by the Scottish Executive Health Department (SEHD) in 2002, favours a long term societal approach in preventing suicide in Scotland. However, it also requires agencies to work together to improve the mental health of

communities. In Glasgow, the Notre Dame Trauma centre is an example of a facility offering support to children and families who have experienced any kind of trauma, including bereavement. The Centre follows the guidance for treating PTSD in the NICE guideline.¹⁰ This centre is an example of psychologists, play therapists and other support personnel working together to offer specialist, structured intervention to help people cope better. The Centre also facilitates educational programmes for peer support in the area of grief and bereavement in schools.

¹⁰ <http://www.nice.org.uk/pdf/CG026NICEguideline.pdf>

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Traumatic Death		
Systematic or systematic type review		
Literature or literature type review	Barlow and Morrison (2002), Bonnano (2004), Clark (2001), Jordan (2001), Kaslow and Aronson (2004), Norris et al (2002a and b), Reyes and Elhai (2004), Rubin et al (2003), Stewart (1999)	9
Experimental/ RCT		
Case Control/ Cohort	Bailey et al (1999)	1
Observational (no comparison group)	Bonnano (2003), Callahan (2000), Hatton (2003), Kaltman and Tehrani (2004), Mitchell et al (2004), Provini (2000)	6
Mixed methods	Harwood et al (2002)	1
Qualitative	Barlow and Coleman (2003), Fielden (2003), Parkes (1993), Pietila (2002), Riches and Dawson (1998)	5
Opinion/text	De Fauw and Andriessen (2003) Dyregov (2004), Frean (1998), International Work Group on Death Dying and Bereavement (2002), Parkes (2001), Reimers (2003), Stroebe et al (2001), Violence and Grief Work Group (1998)	8
Books, Book Chapters, Reports etc	SEHD (2002)	1
TOTAL		31

Key Messages from Traumatic Deaths

A greater proportion of people bereaved through traumatic deaths, compared to other types of death, may require specialist support in the form of counselling.

A multi-agency approach should be adopted towards the care of the bereaved following traumatic deaths where all services look at their approach to those affected (such as police, coroners, legal system, health and social care professionals). This might also include health services disaster plans.

People affected by bereavement following suicide may benefit from interventions specifically designed for their needs.

Chapter 10: HIV/AIDS

In 1981 doctors in Los Angeles began to report unusual cases of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma. These illnesses were destroying the immune system of young men in the gay community and the Center for Disease Control began to track this phenomenon. Following comparisons with researchers in France the virus, causing Acquired Immune Deficiency Syndrome (AIDS) was identified and called Human Immunodeficiency Virus (HIV), (Keller and Fleming 1999). Mallinson (1999) describes the socio-political context in which HIV/AIDS has developed and the fact that many people have died in an atmosphere of shame and social stigmatisation, which has left the needs of those bereaved neglected.

The area of research in bereavement care has grown from unique features of HIV/AIDS, specifically that younger people are more commonly affected and that they may have experienced many losses (Goodkin and Blaney 1996). Kelly et al (1996) compared those bereaved by AIDS and cancer and reported that the AIDS group had less social support and were more likely to conceal the cause of the death to family and friends.

Much of the research has been conducted in the United States of America although with improved antiretroviral therapies the number of deaths of people with AIDS has fallen in higher income countries. This is not the case for the continent of Africa. Sub-Saharan Africa saw 25.4 million people living with HIV/AIDS by the end of 2004, with 2.3 million deaths compared to 0.016 million in North America.¹¹ Within Scotland there are known to be 4,414 people who have been diagnosed with HIV of which 861 have died of AIDS.¹² The majority of cases are in the regions of Greater Glasgow and Lothian.

¹¹ <http://www.avert.org/worldstats.htm>

¹² www.show.scot.nhs.uk/schieh/PDF/pdf2005/0530.pdf

Globally AIDS is the fourth leading cause of mortality. However, the effects are not only on the physical wellbeing of persons living with HIV/AIDS (PLWHA) but also on the quality of life of those infected. The World Health Organisation is working to develop a global plan which includes a Quality of Life Instrument (The WHOQOL HIV Group 2003). This incorporates assessment of physical, psychological, levels of independence, social, environmental and spiritual, religious and personal beliefs. Their approach is cross cultural and has involved experts from around the world.

Goodkin and Blaney (1996) reviewed some of the earlier work in the field of HIV/AIDS. In the USA, certain groups, such as homosexual men, were studied initially followed by an increased interest in women and members of ethnic groups where infection with HIV was seen to be increasing. Research has focused on the fact that people may experience many losses over a short period of time and that bereavement can be exacerbated by lack of social support and individual problems of coping. This has led Goodkin and Blaney and others to develop the 'stressor-support-coping' model as well as examining immunological function and bereavement and declines in physical health. These effects are particularly relevant to those who are infected with HIV and bereaved. There is a growing body of research into the physiological effects of bereavement, especially in the field of immunological function and clinical health and the connection between this and bereavement interventions (Goodkin et al, in Stroebe et al 2001). The 'Stressor-Support-Coping' model has been further expanded by the authors within the *Handbook of Bereavement Research* as a predictive model to identify those who may develop more complicated reactions and signs of post traumatic stress disorder.

Within psychological fields Folkman (1997) introduced the issue of positive states as shown by people who are undergoing difficult life experiences including HIV and AIDS. Folkman (1997) described as a 'startling and initially counterintuitive finding' that positive and negative psychological states can coexist in men who are caring for partners dying from AIDS and consequently during their bereavement. In a more recent study Moskowitz et al (2003) suggested that the ability of bereaved individuals

to achieve positive psychological states shortly after bereavement may have a greater effect on recovery than does depressive mood experienced. Bonanno et al (2005) have also studied the adaptation of bereaved spouses, parents and gay men to extreme life circumstances and their ability to function adequately following the death of a close relation which they state does not, 'reflect denial or pathology but rather an inherent and adaptive resilience in the face of loss' (p.872).

More recent studies have involved groups other than gay men, drawing attention to gender differences (Sikkema et al 2004). It may be that women are at increased risk of complicated grief reactions including thoughts of suicide (Summers 2004). However, many of these studies have small sample sizes and in some cases participants are recruited through advertising, paid for their involvement and display a high level of psychiatric morbidity and level of substance use already.

Most of the work in the field of HIV/AIDS and interventions has focused on physiological aspects of the disease and how immune function may be affected by cognitive behavioural therapy and group work (Centre for the Advancement of Health 2003; Goodkin et al. 2001). They conclude that further research is required to determine whether a bereavement support group intervention decreases clinical disease progression. In discussing hospice care for those with HIV/AIDS in the USA, Demmer (2001) draws attention to the fact that the latest treatments do not help everyone and urges care and support when hope is replaced with disappointment for the patient, family and friends.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence HIV/AIDS	Papers	Total
Systematic or systematic type literature	Centre for Advancement of Health (2003)	1
Literature or literature type review	Goodkin and Blaney (1996), Keller and Fleming (1999), Mallinson (1999)	3
Experimental/ RCT	Sikkemma et al (2004)	1
Case Control/ Cohort	Kelly et al (1996), Summers et al (2004)	2
Observational (no comparison group)	Bonnano et al (2005), Folkman (1997), Moskowitz et al (2003), Sikkemma et al (2003)	4
Mixed methods		
Qualitative		
Opinion/text	Demmer (2001), WHOQoL HIV Group (2003)	2
Books, Book Chapters, Reports etc	Goodkin et al (2001)	1
TOTAL		14

Key Messages in HIV/AIDS

The Stressor-Support-Coping model may be used to guide interventions for those bereaved through HIV.

Services need to be in place and aware of the stigma and socially isolating nature of HIV/AIDS and the implications of multiple losses.

Chapter 11: Learning Disability

The range and level of literature in this chapter is low. The majority of ratings for papers are in the level 4 category of evidence.

It has often been assumed that people with learning disability (LD) will not understand death and will therefore not be affected by its consequences (Cathcart 1995; Clements et al 2004). However, there is evidence to suggest that adults with learning disability are knowledgeable about death and do experience 'normal' grief reactions (Harper and Wadsworth 1993) although it may also be expressed in atypical behavioural change (Hollins and Esterhuyzen 1997; McHale and Carey 2002). These reactions and changes are often delayed and prolonged and may therefore not equate to existing normal grieving timing and patterns, such as described in ICD 10 (WHO) (Bonnell-Pascual et al 1999; Clements et al 2004) and DSM categorisation (American Psychiatric Association). There is no evidence that levels of depression and anxiety are higher in this client group (Stoddart et al 2002).

Interventions that are effective in other groups may not be appropriate in those with learning disability (Cathcart 1995). Summers and Witts (2003) highlight the impact of death on behaviour through using a complex case study. They indicate that a short (12 week) psychological intervention may be helpful. Read (2001) reports on the different approaches needed by counsellors to deal effectively with this client group. Use of non-verbal forms of communication may be helpful to facilitate understanding of death and consequences of loss and could involve other multidisciplinary team members such as Occupational Therapists (Hurst 1998). Additionally, Dowling et al (2003) highlight that external bereavement support through counselling, in this case given by CRUSE trained volunteers, can be more effective than integrating support into day to day practice.

Bereavement in those with learning disability is often complicated by multiple losses at the time of death, as they may also be losing a primary carer and home. Kauffman (1994) identifies the need to ensure that those working with LD clients are aware of the impact of such loss and are able to incorporate this into planning. This could include facilitating attendance at funerals (Raji et al 2003) and planning for future bereavements (Gault 2003).

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Learning Disability		
Systematic or systematic type review		
Literature or literature type review	Cathcart (1995)	1
Experimental/ RCT		
Case Control/ Cohort	Hollins and Esterhuyzen (1997), McHale and Carey (2002)	2
Observational (no comparison group)	Bonnell-Pascual et al (1999), Harper and Wadsworth (1993), Stoddard et al (2002)	3
Mixed methods		
Qualitative	Read (2001)	1
Opinion/text	Clements et al (2004), Dowling et al (2003), Gault (2003), Hurst (1998), Kauffman (1994), Raji et al (2003), Summers and Witts (2003)	7
Books, Book Chapters, Reports		
TOTAL		14

Key messages in Learning Disability

Consideration should be given by all involved groups (including funeral directors) to including people with learning disability in the normal process and rituals of death.

Appropriate understanding of bereavement and support for those with learning disabilities should be available in all settings.

Counselling and other services should consider how they deal with learning disability clients who are bereaved.

SECTION 4: Interventions, care and education

Section 4 moves from the process of bereavement to examine the evidence for different forms of intervention, information and the impact of care in a variety of settings. Chapter 12 examines the range and effectiveness of main types of intervention. This is followed by a review of informational type material received from statutory and voluntary groups (Chapter 13). Appraising such material against 'evidence-based' criteria appeared impossible and so it is presented as a critical thematic view. The following three chapters deal with death and bereavement in particular care settings. These settings emerged from the initial trawl of literature and covered Community and Occupational Health (Chapter 14), Acute Hospital Care (Chapter 15) and Cancer and Palliative Care (Chapter 16). It was perhaps expected that the latter chapter should contain more evidence than that related to other areas of care. The final chapter (17) in this section sought to illuminate the factors related to education and professional developments. Although the issue of education is raised in most other chapters as a factor influencing care, limited evidence of approaches to and effectiveness of education appear to exist.

Chapter 12: Interventions

There are a few recent reviews in the area of interventions in bereavement, which are drawn on for the purpose of this chapter. At the root of all strategies to assist people who are bereaved is the desire to help individuals deal with the physical, emotional, social and practical problems which may arise following the loss of a loved one (Schut et al 2001). At a national and international level this can take the form of agreed assumptions and principles and national strategies (International Work Group documents, Department of Human Services 2004). In the political context, the desire to see all services working together is frequently expressed. At an individual level, there are a variety of strategies from counselling through various types of group therapy and social support (Forte et al 2004). Despite many care options, from health, social, statutory and voluntary bodies, there remains a lack of consensus as to what constitutes the optimal type of support (Forte et al 2004).

Studies into the efficacy of bereavement interventions suffer from a lack of rigorous methodology. Forte et al (2004) included 74 studies in their review and noted that methodological problems in study design, replication, theoretical heterogeneity and variations between studies hamper the ability to draw firm conclusions. These views are echoed by others (Centre for the Advancement of Health 2003; Allumbaugh and Hoyt 1999).

In their review of the efficacy of different interventions, Schut et al. (2001) conclude that based on the evidence to date, 'the more complicated the grief process appears to be, or to become, the better the chances of interventions leading to positive results' (p.731). One of the problems with studies that have been conducted in this field is related to the recruitment of participants who may not have sought bereavement interventions themselves. Such studies may result in no effect or a negative one. The timing of interventions may also be significant with interventions in the early period of loss affecting and possibly diminishing the natural social support of family and friends.

Schut et al (2001) distinguish between primary, secondary and tertiary interventions. The focus for primary prevention is all bereaved people; secondary prevention relates to people who are at higher risk of developing problems and tertiary prevention would be for those who have developed problems. This appears a useful categorisation and one which accords with NICE guidance for palliative care highlighted in Chapter 16.

Emotion and Self Expression

At the heart of any consideration of the bereavement experience is the expression of emotion and feelings. The loss of someone, can also involve what Bowman (2000) calls 'shattered dreams' when people struggle to make sense of what has happened and experience more than just the loss of the person.

People are characterised by their ability to communicate in many ways and by many means. In the early stages of loss this could be verbally (Parry 1994) or in writing (Range et al 2000; Stroebe et al 2002; O'Connor et al 2003). There is some evidence, particularly in the area of traumatic deaths, that writing about the experience can help people (Range et al 2000; O'Connor et al 2003) although Stroebe et al (2002) could not support this in their study of emotional disclosure.

Throughout this review the importance of individuals being able to tell their 'story' is mentioned frequently. This has been called 'death review' by some (Parry 1994) which incorporates the need people have to describe the circumstances of the death. This process of describing and adding meaning and emotion to what happened may be repeated frequently in the early stages. This may be harder for some than others and men particularly may have problems expressing their emotions (Crossland 1998). Certainly, not talking about it must not be confused with not grieving. Combining therapy which promotes verbalisation with other forms of therapy, such as art therapy has been shown to be more beneficial than 'conventional' therapy alone in those with complicated grief (Schut et al 1996).

Counselling and Psychotherapy

It is difficult to generalise about the provision of counselling for people who are bereaved due to the variety of individuals and professionals involved from the voluntary and statutory sector (Machin 1998; Parkes 2000; Gallagher et al 2005). It is also difficult to conclude who will most benefit from counselling. However, Parkes (2000) concludes from some of the more recently published studies, and years of experience in the field, that people who have suffered especially traumatic and unexpected types of loss and are vulnerable in other ways may benefit from counselling. Those who do not have other support from families and friends may also benefit. Jordan and Neimeyer (2003) conclude that the efficacy of formal interventions for the bereaved is distressingly low, far below that of most other types of therapeutic interventions but that most grief is self-limiting with a naturally occurring decline in grief symptoms and that the greatest efficacy in studies is where the bereaved self-identified for bereavement-related distress.

The type of counselling may not be a significant factor (Schut et al 1997). Allumbaugh and Hoyt (1999) suggest that grief interventions with self selected clients that begins within a few months of loss is likely to be as effective or possibly even more effective than psychotherapy in general (p378), although men may benefit most from a type where they can express feelings (Schut et al 1997).

One of the most widely recognised organisations in the UK for bereavement support/grief interventions in the UK is CRUSE. Gallagher et al (2005) surveyed the views of ex-clients in one branch and found that the majority felt that counselling had been helpful, with the only negative comments relating to the time from referral to being seen. For the participants in this study the reputation of the organisation, its location and the fact that it did not charge a fee, was a positive influence. The majority of the participants in the study had a high regard for their counsellors strengths and qualities, although a few were concerned by their counsellor's approach.

Bereavement Groups

One of the difficulties of assessing the value of bereavement groups is that most studies have looked at the experience of those attending who are self selecting and may be more likely to express positive views (Zonnebelt-Smeenge and De Vries 2003; Thuen 1995; Thuen and Sandvick 1998). The benefits of people coming together, who are in similar situations, includes: sharing and normalising experiences and offering support to others, hence 'self-help' groups (Hopmeyer and Werk 1994). The running and leadership of groups in bereavement can vary from professional/counsellor led to volunteer/lay person. Groups frequently involve a higher proportion of leaders who have been through an experience of loss (Thuen 1997). There are also other models of support such as workshops offered within the early stages of bereavement (Beem et al 1998).

Differences in the way that people experience the support of groups has also been examined. Zonnebelt-Smeenge and De Vries (2003) looked at age and gender differences and found that older widowed people in the support group found it more difficult to enter a positive phase in their lives. Thuen (1995) describes setting up the Norwegian Bereavement Care Project and the survey which was conducted to look at the views of the support group members. Whilst recognising the limitations of the sample, the author found that the social and emotional support offered by the groups was most valuable and the style of leadership crucial in influencing the groups.

Social Approaches

The range and quality of the literature in this section is very mixed due to the range of treatments and lack of homogeneity between studies.

The review by Forte et al (2004) of the literature in interventions and bereavement care used the terms intervention or support or counselling or therapy. Due to the diversity of the treatments reviewed, the process was therefore difficult to compare. Of the 39 studies, only 23 had control groups and 15 had claimed random allocation, however only three actually demonstrated application of the allocation method. Ten of the studies

were mutual/self-help groups and 29 were professional led support groups. The formats of the programmes were variable throughout the review from leadership styles and required attendance, to the overall format of the style of the group.

Although there appeared to be some treatment effect in seven of the interventions, Forte et al (2004) felt this was due to differences in the interventions. However, six of the studies showed no effect. Some studies even documented improvements in bereavement symptoms in the control groups.

Tudiver et al (1992) also report such findings in their study of widowers who had participated in a nine weekly semi-structured peer group programme, which had a focus on mutual help. All subjects showed significant improvement over time (baseline to eight months) in social adjustment, social support and psychological well-being, with no difference between the intervention and control groups. It was reported that the more recovered men had dropped out of the study earlier and the more distressed men remained in the mutual-help group which may have impacted on results. Similar findings have been documented in a review by Kato and Mann (1999), with some suggestion that social activities groups were actually harmful to participants.

In exploring the nature of social support a Finnish study (Kaunonen et al, 1999) of widows and widowers found that the widowed person received social support most often from their own family (68.6%) and friends (41.5%). Thuen (1997) reports similar findings with professional support reported as only 9.7% helpful. Kaunonen et al (1999) suggest that time provided by the social network was seen as the most important means of support, followed by the means to express themselves by telephone or face to face contact. Although the widowed perceive the support they received as most helpful, however, they felt they benefited from the social support that they also gave to other grieving family members. Social support facilitated expression of feelings and without support the widowed reported functioning like 'zombies' (p.1311).

Age may be a compounding factor in the nature of support, as Thuen (1997) reported that younger respondents received more support from professionals and from colleagues compared to older respondents. Perhaps social support is more effective in relieving the negative impact for older individuals.

In exploring gender effects on social support, Thuen (1997) concluded that social support was only of benefit in the later phases of bereavement and that female respondents receive slightly more support from friends compared to males. Stroebe et al (2001) also found similar findings, in that the widowers tended to have lower levels of social support and that the effects of depression and loneliness related to bereavement appeared to be stronger. However, Stroebe et al (2001) concluded that although there were evident sex differences in bereavement outcomes and social support, there was no evidence that social support influences those differences. In contrast, Casserta and Lund (1996) found that men were as likely as women to engage in social contact with other members outwith social group meetings.

In exploring the timing of the social support Casserta and Lund (1996) found the frequency of contact increased over time, outwith the support group meetings and had no relation to attendance at the meetings. Perhaps as Thuen (1997) suggests, social support is only beneficial to individuals in the later phases of bereavement, which he records as 30 months or more.

None of the studies explored the implications of high and low risk bereaved individuals and the relationship to social support or integrated ongoing evaluations to assess efficacy. Cultural, and spiritual implications or nature of the loss were also not explored, which may have a strong bearing on social needs.

Professional Approaches

The specific literature in this section is low, however other literature from the intervention section had pertinent points to contribute.

Increasing number of deaths are occurring in hospitals rather than at home (Centre for the Advancement for Health 2003), which increases the need for health professionals to understand grief with basic counselling skills becoming increasingly crucial (Youill and Wilson 1996). However, most bereaved individuals are treated on an outpatient basis, and are living at home in the community (Schut, DeKeuser, Bout and Stroebe 1996). Therefore, Parkes (2000) suggests health professionals not only have the opportunity but the responsibility to assess bereavement risk in family members before or at the time of death. Yet Machin (1998) has reported that despite assessing for risk and the clients' need for counselling, they have little opportunity to engage in this within the current political and economic climate in health and social care.

It has been well documented that bereavement following a sudden death is one such risk factors, and health professionals should target such high risk individuals (Parkes 2000; Potocky 1993; Youill and Wilson 1996). In assessing the risk factors and symptoms of high risk individuals, Potocky (1993) states there are currently no standardised definitions of high risk or high distress individuals for professionals. However, Parkes (2000) identifies these individuals as people who have unusually or unexpected types of loss or people who are vulnerable. Earlier, Raphael (1977) had identified four independent characteristics for morbid grief in spousal bereavement as individuals with low social support during the crisis, who have a moderate level of social support coupled with particularly traumatic circumstances of the death, have a high ambivalent relationship with the spouse and have a concurrent life crisis at the time of the death. Such individuals who are identified at high risk are likely to benefit from counselling (Parkes 2000). Individuals who do not present with such risk factors, Potocky (1996) suggests, are experiencing normal grief and are not in need of professional help. However, they may all benefit from the range of voluntary group information and resources that now exist.

There are financial implications of providing support systems in hospitals, hospices and funeral homes, although the cost should be set against the long-term expense of supporting relatives and close friends in the community (Youill and Wilson 1996). Co-operative efforts to make the best use of available resources should be made and not focus on the intrapsychic experience in isolation of the wider community, nor merely on secondary or tertiary prevention. (Potocky 1996). Services provided should be carefully selected, with training and supervision undertaken by accredited organisations (Parkes 2000).

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence Interventions	Papers	Total
Systematic or systematic type review	Allumbaugh and Hoyt (1999), Centre for Advancement of Health (2003), Forte et al (2004), Jordan and Neimeyer (2003), Kato and Mann (1999), Potocky (1993)	6
Literature or literature type review	Stroebe et al (2001)	1
Experimental/ RCT	O'Connor et al (2003), Stroebe et al (2002), Tudiver (1992)	3
Case Control/ Cohort	Range et al (2000), Schut et al (1996), Schut et al (1997)	3
Observational (no comparison group)	Casserta and Lund (1996), Gallagher et al (2005), Hopmeyer and Werk (1994), Kaunonen et al (1999), Thuen (1995), Thuen (1997), Zonnebelt-Smeenge and De Vries (2003)	7
Mixed methods		
Qualitative	Machin (1998)	1
Opinion/text	Beem et al (1998), Bowman (2000), Crossland (1998), Parkes (2000), Parry (1994), Thuen and Sandvick (1998), Youill and Wilson (1996)	7
Books, Book Chapters, Reports etc and pre 1990	Department of Human Services (2004), Raphael (1977), Schut et al (2001)	3
TOTAL		31

Key messages in Interventions

Unselected bereaved people do not necessarily need or benefit from counselling. For some people experiencing normal grief, interventions may be harmful.

Co-operation and co-ordination of accredited training and care from professionals is needed to meet the increased need for understanding grief, abnormal grief and to utilise counselling skills.

National standards and national plans are needed for professionals to work together in a co-operative manner.

Further research into the efficacy of social support in relation to age, gender, timing and mode of death is evident, and into identifying a tool to recognise high risk individuals for use by professionals.

Services should provide a focus of care for high-risk and high-distress individuals that use a systematic assessment tool to addresses clear goals.

Holistic programmes for bereavement care should provide a continuum of care spanning primary, secondary and tertiary prevention, especially primary prevention.

Attention should be paid to the whole family in the bereavement process and consideration by bereavement and support agencies in how to facilitate family and friends as mechanisms for social support to the bereaved.

The financial cost of support systems in hospitals, hospices and bereavement homes might be set against the long-term expense of supporting relatives and close friends.

High risk groups often benefit from interventions and the results of therapy to people with psychiatric disorders following bereavement are often good. High risk men benefit from different interventions to high-risk women.

There is some evidence that cognitive therapy with other forms of therapy, such as art therapy, may work better than cognitive therapy on its own.

Chapter 13: Information for the Bereaved

Overall there was a wide range of grey literature, including documents, letters and websites that were received or identified. Much of this material related to information type literature, either in written or web-based forms.

A number of themes and issues have been discerned from the material and these are outlined below.

Internal policy and procedure

Many documents focus on what is available and from whom. This is spelled out for recipients in terms of contact numbers and addresses. Some hospice groups produce booklets which outline exactly what is available and it is clear that considerable time has gone into the planning of these documents. Similarly some NHS documents focus on service provision and who will provide services. These documents often use language more suited to contracts rather than deal sympathetically with the death of a loved one.

Procedure for relatives

Materials offer advice on, for example, how to collect the death certificate and register the death. They also address aspects such as organ donation and transplants. A good example is *What to do after a death in Scotland*. This booklet, now in its 5th edition, covers in appropriate depth many of the important issues surrounding death that relatives may need to know about. It may prove beneficial for other leaflets to use this as a starting point, supplementing with local information and advice. Many local documents replicate this document, to the point that a member of the public will be reading the same material over and over again.

Using a generic framework

One NHS Board showed an integrated approach to writing and their documents fit well with specific items relating to procedures for relatives and also integrated procedures for staff. Using a generic template two of their booklets showed that they were able to target specific types of patients. Firstly, they have a booklet which services premature birth and a second which focuses on still births. Between them there is less than two pages of adaptations. Similarly the Scottish Death Trust focused on the grief of grandparents with a different leaflet for parents and children. This was replicated by SANDS and the Miscarriage Association. One possible down side to the production of specific documents is that their target audience is comparatively narrow.

Respecting the death

In one case the telephone numbers of an agency or group were scored out and new ones scribbled on. The image portrayed by such out of date materials may not reach the standards required by the service. The reflection on the quality of service post death could have ramifications on perceptions of the service as a whole. The quality of the material varies, from second or third generation photocopy through to glossy booklet or information packs. Charities are more likely to use printed materials. However, they are also more likely to use space within their documents to request bequeaths support or offer mail order leaflets and books.

Postcode provision

In some cases higher quality materials are postcode tied to NHS regions, or to agencies and charities that use folders and 'glossies' as a promotional tool, promoting their services. Clearly there is a duplication of resources and many agencies and charitable groups do similar jobs, conveying similar information. It would make sense to develop a series of generic booklets such as the very basic HEBS booklet *Talking About Bereavement* which covers briefly some of the issues pertinent to bereavement and grief, possibly pointing out when people should contact professionals for support and help. By then having a supplement page or

insert with local telephone numbers and details of local groups, readers will have the information that they need to proceed. In developing targeted booklets to particular groups the information is more likely to be useful and less generic. After all death is a unique event to each of us, even if it will happen to us all.

Another NHS Board produces a small booklet called *When someone has died: Information and support for relatives and friends*. The booklet is split into three main sections. The procedural aspect of what to do when someone dies is covered in six pages alongside registering a death and planning a funeral. The following four pages look at thoughts and feelings, and there is a single page at the back with useful contacts. This type of format seems acceptable as well.

Using what is already available would considerably cut costs and ensure that local services are promoted uniformly. The inclusion of contact details within a supplement would allow the maintenance of contemporary information, by regular updating. It may be possible to include organisations and service industry groups such as undertakers to offset some of the costs in return for their telephone number being included in the booklet.

Targeting groups

Some grey literature is presented for particular groups, thus a pack dealing with older people will talk in terms of widowhood and a family pack focuses on children. The images used similarly can reveal the target group as well. One English NHS Trust and the National Association of Funeral Directors use flower images throughout as a motif. The use of a single flower is also on the cover of an accident and emergency booklet for Queen Margaret and Victoria Hospital. Winston's Wish, a charity which focuses on 'grieving children and their families' uses cartoon and family pictures to convey its message and products.

Undertakers' materials

Undertakers' materials offered a useful insight into the ways in which they provide their services. The National Association of Funeral Directors (NAFD) has information on bereavement benefits, and also produces its own in-house journal. This yielded a different perspective on bereavement care and funerals. It may be possible to integrate information on a leaflet that explains bereavement that is developed by one of the big umbrella organisations such as the N.A.F.D.

Anything Research-based?

In most cases the grey literature was designed for lay people and as such did not make use of empirical research. Some materials show their age by still referring to the now dated stage model as outlined by Kubler-Ross (1969). The greatest challenge facing producers of such literature is to stay current.

Documents that deal with internal policy are much more likely to justify and account for the guidelines contained within. For example a Scottish counselling service has a document offering *Guidelines for referral to palliative care counsellors*. It cites a range of texts related to counselling mostly from the 1980s, but does not give references. Similarly the 'reasons for referral' are laid out clearly as bullet points, but again the texts that they refer to (whilst being more up to date) are not properly cited or available.

From this it might be suggested that the policy contained therein is more important than the verifiable evidence on which it is based. However, it is clear that the use of empirical evidence has helped formulate these policy documents. For instance, services are geared towards a preference for self referral because according to one document: Garfield (1994), Schut et al (2001) and the DoH (2001) indicate that 'Self referral is preferred because the initial motivation to seek counselling is important in the final outcome'.

Hospice literature is more specific about services that can be offered possibly because their remit means they have clear systems of

demarcation of what they can and cannot provide. As a result they can clearly outline this for clients. For example the Sue Ryder family support unit and chaplaincy at St Johns Hospice have documents that spell out clearly the services available. From their document clients are clear about what the social work service offers and what the bereavement service offers. The document, whilst formal, stops short of using the language of a contract.

Contents

Many of the leaflets examine both grief and bereavement, but they do so within a context. Within their pages they try to offer a banding of normality. What is acceptable? What is the right amount of grief? In some ways there is an interesting parallel to be drawn with the historical traditions of death and dying from Aries (1974). Offering advice on how to grieve properly has very close similarities to Ares Morendi documents, written in the 16th century to inform people of the right way to die.

Modernity is keen to lay benchmarks for the practice of mourning. Many questions and answers focus on how much is right and what an individual should feel. Some prescribe behaviour, e.g. put off major decision making etc. In this case the telling of the right type of mourning sets a benchmark for people to follow and judge whether their responses need checking, due to high levels of ruminance on the subject of morbidity.

This has a Victorian feel since in that era people were told what was expected of them in regard to bereavement. Possibly the main difference is that within the grey literature, the documents outline what people may come to expect in terms of emotions, feelings and symptoms associated with death.

Where the death of a child is involved it is more likely that leaflets will broaden out to specifically deal with partners and also other siblings. The leaflets are also more likely to include friends and family in the advice. At the other end of the spectrum, some designs and art work incorporated in the information leaflets showed a different perception of bereavement in older people. For instance death in older people was more likely to be

shown as a solo event (or flower) or at best one which ends the partnership of an old couple sitting on a park bench.

Format

As already discussed most of the literature examined was in paper format. It may be possible to make an electronic version of this information available which could be updated more regularly than a paper document can. Each Health Board area could then personalise the material so that it was meaningful for a given area. The ability to download documents from a single place may be of use to those with the technology and bandwidth to access data online.

Quality and thinking out of the box

Within one NHS Board area there is a Bereavement information subgroup; partly formed because after the 2003 audit of information materials, it was found that 'Information for the bereaved across the 3 acute hospitals appeared inconsistent, insensitive and inadequate'¹³. Some of the materials examined would fall within their comments. It is not fair to say that all materials were like that. Ironically one of the most 'lay' of documents, a newsletter, focused on very modern theories and to their credit explained it very well (Scottish Cot Death Trust).

This NHS Board have approached the supply of bereavement literature in a more unique way. As a result of the redesign a range of practical applications for bereavement literature have been explored. For example they have designed simple sympathy cards which have a contact number printed on them. They also contain very basic information regarding procedures after a death such as registering the body in the case of the intensive care unit (where the death was expected) and outlining the procedure for the involvement of police and the procurator fiscal in cases where the death is sudden (for example the accident and emergency department). Another organisation has also adopted the former HEBS booklet, *Talking about Bereavement* along with an information booklet on

¹³ From correspondence

the post mortem procedure. Finally a nice touch at reinforcing the procedural aspect of registering the death comes in the shape of printed envelopes which house the death certificate. On one side the name of the deceased can be inserted along with information of when to register the death. On the other side are the addresses of all the main registrars for the area.

Emotive feelings and issues

The information relating to bereavement or loss, points to the normality of feelings and to the need for talking. Clearly leaflets act as signposts to services that are available. What also becomes clear is that leaflets even within the same organisation show a duplication of resources. Within a single geographical area, or within one NHS Board area a number of local services and agencies are all producing similar leaflets but of differing quality.

A number of recurrent themes are evident in much of the material in relation to symptoms of grief and bereavement. These have been detailed into ten main points. In Table 2, an example of the main themes is taken from an information leaflet from one hospice:

Table 2: Example of main themes taken from information leaflets

1. very distressing feeling
2. death can be a shock
3. may feel numb
4. or overwhelmed
5. over-powering feelings and flooding sensation of memories
6. time spent rethinking events
7. denial of loss
8. loss of appetite concentration and motivation
9. confirmation that distress will pass
10. importance of talking to others and sharing memories.

The themes follow a pattern of triple response being

- Reaction.
- Confrontation.
- Readjustment.

Often there is a thinly disguised stage theory lurking in the background.

Possibly a final style can be discerned which is the survivor (e.g. SOBS; Motor Neurone Disease Association) or experiential style of writing (e.g. SANDS), which draws on peoples' similar experiences or in fact shared experiences to get a point across. Often the point is you are not alone.

An overall emphasis is placed on describing what is normal and how to deal with the initial aftermath of the death of a loved one. These documents are given to people at the time of death. It may be important to think of a secondary leaflet which could be used as a follow up so that people are not overwhelmed at the start. Documents are often separated into sections which deal with the practical issues and then go on to look at the emotive ones.

Key Messages from Information for the Bereaved

Information for the bereaved should be of high quality, with a central core of general information and an additional local section.

There is a range of information (electronic and hard copy) that is produced by specific groups that should be reviewed, known about and made available for the bereaved at appropriate times.

Chapter 14: Community and Occupational Support

How people are supported in the community and in the work place in bereavement cuts across many sections of this review. This chapter focuses on a small number of papers relating to bereavement care in the community, particularly the role of the general practitioner, district nurse, counsellors and occupational health.

The issue of returning to the workplace following bereavement is one that has received little attention and yet Russell (1998) comments that employers should, at the very least, want to maintain an active and healthy workforce. He suggests that all organisations and workplaces should have a structure and system in place to respond to staff who are bereaved. Returning to work will be different for individuals depending on the circumstances and flexibility in approach is the ideal situation (Charles-Edward 2001).

The physical and mental health consequences of bereavement are well documented and GPs are frequently the first formal contact with the health service when problems arise (Birtwistle and Kendrick 2001). GPs may be at the forefront of assessing patients who have bereavement related problems and deciding what the best course of action, if any, for that person is. The GP's own beliefs and attitudes to death and bereavement will play a part here and Saunderson and Ridsdale (1999) found that GPs may have feelings of guilt about the death of patients, and require support to manage their own and their patient's bereavement. Some doctors expressed their lack of confidence and training in tackling this area of care.

Wiles et al (2002) explored the factors that influenced GP referrals to a bereavement counselling service. In this qualitative study they uncovered the views of GPs regarding what constitutes abnormal bereavement. The indicators they used included such factors as; the nature of the death, level of social support, and the reaction to the death. The participants also made a judgement based upon who they thought may benefit most

from counselling. However, this may have excluded other individuals who did not fit into their 'notional' criteria.

The role of the district nurse was explored by Birtwistle et al (2002) through surveying a sample of 522 nurses. Ninety-five per cent of the respondents believed that they should visit bereaved relatives and carers of patients they have nursed (19% thought they should visit even if it was not their patient). Although, they felt they should be involved, there was evidence that this involvement lacked structure and rationale and it was suggested that there were implications for training and support.

Different counselling strategies are known to exist in the community and Payne et al (2002) interviewed counsellors to uncover their approaches for counselling the bereaved in General Practice. Most of the counsellors saw their work within the broader agenda of work concerned with loss and relationship management. Strategies used included, telling the 'story' of loss, active listening, establishing a supportive relationship and enabling the person to deal with unfinished business.

In one study, the views of bereaved patients in a single general practice were looked at to find out what people expected in the way of bereavement care (Main 2000). The majority of the sample felt that bereavement support was an important aspect of the GP's role. Some comments related to specific aspects of care, such as those that would have appreciated contact from the surgery to discuss aspects of the death. Certain practical steps, such as ensuring bereaved patients could be readily identified within the system, were considered in the surgery to make staff aware of people that were recently bereaved so that they could be more sensitive to their needs.

Organisation of services

The Gold Standards Framework project in Community and Palliative Care,¹⁴ has been introduced into many GP practices in the UK, including Scotland, to improve the provision of care to people who are dying and their families. This relates largely to the palliative care phase with recommendations for organising care that is holistic, multidisciplinary and provides choice and control for patients and families. However, it includes a consideration of 'afterwards' for the family, with the recommendation that assessment/audit and bereavement support take place. This Macmillan scheme was the brainchild of Dr Keri Thomas, a Macmillan GP, and whilst it is undoubtedly based on sound principles of care, there has as yet been no official evaluation. However, it is widely recognised in practice in the community to guide care for the dying, carers/families and to support the primary health care team.

For the purpose of this review contacts were made with Health Boards and specific services in the community relating to bereavement care. For example, an audit has been conducted in one NHS Board to look at 'Support for the Newly Bereaved' and developing screening tools. Within another NHS Board there is a bereavement counsellor working with the palliative care services in the community to offer support to people who have received visits from the palliative care teams. Both appear to be 'isolated' components, although as we did not carry out a thorough review of all services and work undertaken within each NHS Board this suggestion is somewhat speculative.

¹⁴ www.macmillan.org.uk

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Community and Occupational Support		
Systematic or systematic type review		
Literature or literature type review	Birtwistle and Kendrick (2001)	1
Experimental/RCT		
Case Control/Cohort		
Observational (no comparison group)	Birtwistle et al (2002)	1
Mixed methods		
Qualitative	Main (2000), Payne et al (2002), Saunderson and Ridsdale (1999), Wiles et al (2002)	4
Opinion/text	Charles-Edward (2001), Russell (1998)	2
Books, Book Chapters, Reports etc and pre 1990	Gold Standards Framework (Macmillan)	1
TOTAL		9

Key Messages in Community and Occupational Health

Organisations should have a clear policy on how bereavement in the work place is handled.

Approaches to the assessment of the health needs of bereaved patients and the impact of primary care interventions need to be evaluated to ensure that resources are used effectively.

There are implications for training and education of primary care staff (GPs and District Nurses) in the community in the field of bereavement care as it presently lacks structure.

Practical steps within General Practice may increase sensitivity to the needs of bereaved people.

Chapter 15: Acute, Hospital Care

This chapter of the review covers a range of literature that relates to care in hospital, particularly in A&E, ICU and CCU. It would appear that it is within such units that death and bereavement have most significance as the environments are often clinical and unfamiliar to relatives (Fauri et al 2000). Death is often sudden and unexpected (Edlich and Kubler Ross 1991) and the resultant grief more pronounced. As such, death in acute hospital based settings has the potential to have great impact on the ensuing bereavement process for relatives.

Kent and McDowell's (2004) literature review of bereavement in acute care settings highlights those aspects of care which need to be undertaken. They suggest that whenever possible relatives should not be informed by phone of death unless they have far to travel, and that the allocation of one nurse to the bereaved family is often identified as helpful as is the provision of an appropriate room which has identified facilities. They go on to suggest that relatives should not necessarily be excluded from resuscitation (The Resuscitation Council UK 1996; RCN 2002). If wishing to be present they should be accompanied by a nurse to explain what is happening.

The manner in which the death is communicated is also considered more important than the professional identity of the person undertaking the role. Answering questions, listening, sitting with and showing emotion are identified as assisting this process. Furthermore Kent and McDowell (2004) suggest that viewing the body is important in the facilitation of the grief process, a point supported by Haas (2003) but that this should be encouraged, rather than forced onto relatives. Involvement in last offices is also identified as possibly helpful in accepting and adjusting to the death, as is appropriate packaging (bag or box) to convey the deceased's clothing with an explanation for any damaged or soiled clothing. There is also a need to accommodate cultural/religious rituals and any specific personal requirements.

Organ donation should be considered and has been shown to assist bereavement (Marrow 1996). In addition it is suggested that follow-up occurs, with a recommended time of 1-2 weeks after the death, when a handwritten note or telephone call is appropriate and can be welcomed by families. Such follow-up is often part of bereavement services offered in palliative care settings and it may be suggested that the ideals and standards of palliative care should be transferred to the general hospital setting (Street et al 2004). This is echoed in a UK context by Rogers (2000) who identifies dissatisfaction with dying in hospital and advocates the use of palliative care approaches/standards across all settings.

A&E

Nurses identified dealing with death and bereavement as the most difficult aspect of caring for families in A&E (Hallgrimsdottir 2004) although this may not be case for doctors, as they have reported less emotional involvement (Redinbaugh et al 2003).

The Royal College of Nursing and the British Association of A&E Medicine (RCN/BAA&EM) developed guidelines for bereavement care based on a review of death, dying and bereavement in A&E departments in England and Wales in 1995. It suggests that whilst there were examples of good policy and practice, there were considerable shortfalls in allocation of staff to bereaved relatives and to telephone responses related to a death. Only a minority of bereaved were asked about organ donation and it appears that relatives are often excluded from resuscitation and last offices within the department. The follow-up support to the bereaved is often limited and information given to relatives often more related to post death tasks. Whilst medics are more likely to inform relatives of death, nurses appear to be more likely to be involved in the process of dealing with the bereaved.

Facilities are often not private and variable in providing essential fixtures and fittings. Formal training was not available in half of the A&Es surveyed and where it was available often did not include issues related to organ donation and spiritual/cultural issues. In addition staff support was not always available beyond debriefing sessions. The value of having a

multidisciplinary protocol, an educational programme and an information pamphlet for the bereaved has been identified as advantageous (Adamowski et al 1993). Providing education, such as that described by Adamowski et al and Tye (1996) has been identified as essential in meeting the needs of staff in A&E departments.

Robinson et al (1998) in a controlled pilot study in A&E, found a trend towards lower symptoms of grief and intrusive imagery and post traumatic avoidance if relatives witnessed the resuscitation process. There was no evidence of detrimental effects up to nine months later. Merlevede (2004) in a Belgian setting also identifies the value of allowing relatives to be present during resuscitation and being accompanied to see the body if desired. This would suggest that this is an area for further development in Accident & Emergency units.

Li et al (2002) ranked the bereaved perspectives of helpful actions in a Hong Kong A&E. Information giving after death, during resuscitation, seeing the body and respecting customs and religions were ranked as most helpful. Least helpful were being offered sedation and being discouraged from seeing the body, whilst being offered a drink is seen as an insult. The results obviously need to be interpreted in the light of differences in culture, as Chinese culture has different mourning rituals and responses, but it highlights how important the perspective of the bereaved can be to the development of services. A similar cultural perspective is offered by Ping et al (2002) where a bereavement service offered from A&E was not well utilised. Providing a follow up service from A&E has been described as beneficial to staff and relatives (Williams et al 2000) although no evidence of the effectiveness of such a service is offered.

However, Lopez Soccoro et al (2001) remind us that bereavement support should be considered for staff in this area. Though set in Spain the lack of education in how to break news and support relatives when viewing bodies is highlighted. It encourages the use of reflection and sharing as a means of coping. This theme which is also identified by Wakefield (2000) and Fauri et al (2000) who consider that nurses may harbour

disenfranchised grief (Doka 1989) and need some means of expressing their feelings and reflecting on experiences.

ICU

Cuthbertson et al (2000) sought to establish the value of a follow-up bereavement service from ICU (identified as part of the Intensive Care Society guidelines for bereavement care in 1998). They make the practical point that a lack of adequate recording at admission can make follow up problematic. However, those followed up identified that relationships and communication with staff were key factors before and at time of death, and that the majority of the bereaved have support from family and friends but few use professional services after the death (findings for the latter are also reflected by Billings and Kolton 2002). The evaluation by Cuthbertson et al (2000) does not establish in what ways the intervention of follow-up was effective and there is an implicit assumption that it is of value and is cost effective. Tunnicliffe and Briggs (1997) and Williams et al (2003) highlight the perceived value of follow up from perspectives of the bereaved and the staff of the unit, but again evidence of effectiveness is not described.

Granger (1995), in a survey of UK ICUs, identified that staff consider they need more training to deal with breaking bad news and dealing with bereaved relatives at both pre and post graduate/registration level. They also consider a need to improve facilities for relatives, particularly practical issues such as relatives having an available phone and direct physical access to the deceased in a private setting. Granger (1995) also found that the range and type of information available in ICU and given to relatives, suggested duplication of effort and the possibility that the quality of some of this home produced information may be poor. (This is also the case evidenced from the range of 'grey' material received see Chapter 13: *Information Leaflets*).

Communication and information giving appear to be issues identified as in need of address in ICUs (Jastremski 1998). General Practitioners also indicate they would welcome quicker accurate information on deaths in ICU so that they could follow up the bereaved relatives, although, in the

main, they do not then refer on to other services (Peters and Lewin 1994).

CCU

Edwards and Shaw (1998) in a review of literature in this area identify key issues from the literature. These accord with those from A&E and ICU in that relatives may wish to be present during resuscitation, viewing the body is regarded as a positive factor in facilitating bereavement, and the provision of appropriate private facilities are important. However, this review by Edwards and Shaw (1998) questions the need for an allocated nurse as some relatives may not wish this. The reviewers advocate distribution of DSS booklet *What to do after a death* and other information on support such as bereavement counselling. It also suggests that clinical staff are not good at breaking bad news and communicating at the time of death. In addition lack of available education and support is again noted. There appears to be more ambivalence to follow-up support for bereaved relatives in this area and hospital staff may not be best placed to undertake it.

Olsson (1997) reports that whilst information from health care staff is valued in the CCU context, the showing of emotions by staff is open to question, since family members are often facing crisis with the death which is often unexpected. The coping needs of the family when death occurs in CCU may be difficult to assess, particularly in relation to the degree of support available through family and social networks. The support that may be required from health or social care staff is therefore uncertain at this point and follow-up could seek to address such assessment.

Hospital care in general

Ellinson and Ptacek (2002) indicate that medical staff working in hospital based services perceived that the bereaved should have follow-up via an institutional generated mailing service and programme, rather than personal involvement of physicians. Ferris et al (1998) found similar in junior housestaff in that although they are usually involved in a number of deaths it is often only at the time of death and not much beyond. In addition, although they do have some concerns about death and bereavement care they consider themselves capable for future practice. Whilst they considered they had learned most of their knowledge in this area 'on the job', over half did recognise a need for further training.

Redinbaugh et al (2003) identify that junior doctors have the greatest need for emotional support following death (greatest in females and related to time they had provided care to the patient) but consultants rarely provide such support. Role modelling from consultants, it is suggested, results in potential for less stress and burnout. However, consultants also report a lack of available help in discussing issues related to death and bereavement.

This is supported by Delvecchio Good et al (2004) who in a study of narrative experiences of death in a variety of doctors, found that all levels have issues when dealing with death. Such issues are perhaps not unusual but when doctors are often the ones identified to 'break bad news' (Lloyd Richards and Rees 1996) it can place an increased burden on them. Providing multidisciplinary workshops, as well as bereavement services (Fauri et al 2000), may provide greater opportunity to identify stressors and consider the roles of the team in bereavement care. Edlich and Kubler-Ross (1992) endorse the need for 'systematic educational training programs' in addition to death education being a greater part of medical curricula generally.

A recent consultation document from the Department of Health (DoH), Tissue Branch, Bereavement Policy (2005) highlights issues related to death and dying in hospital and the experiences of the bereaved. It identifies 12 areas for the principles on which bereavement care should be

based: respect of the individual, equality of provision, choice, communication, information, partnership, recognising and acknowledging loss, environment and facilities, staff training and development, staff support, health and safety and review and audit. It also indicates that the DoH has funded the development of a training resource to help provide in-house training for staff which should be available in 2005.

The DoH recommends that all Trusts in England and Wales should have in place a written policy on death and bereavement which should identify bereavement care pathways (eg Gold Standards Framework), be based on consultations with appropriate stakeholders and include awareness of consent to post mortem (Families and Post Mortems. A Code of Practice, DoH 2003). There should be clear responsibility at executive and managerial level, with a senior manager who has appropriate skill and training taking primary responsibility. Identified education and support should be available and utilised.

The perspective from the bereaved provided in this consultation document suggests that the journey from pre-death to bereaved is often affected by: poor communication from all staff and between staff internally and to external sources, not being fully involved in the process, staff not aware of relevant policies, problematic environmental factors, a lack of specialised staff for advice and support and a need for good quality information. Such areas are also identified by Warren (2002). Billings and Kolton (1999) in a US study concur with some of these shortfalls, despite the majority of people registering overall satisfaction with care. They note particularly that issues of respect, dignity and communication covered the majority of these concerns. As Silvey (1990) points out from a small sample of interviews with relatives after a death in hospital 'All remarked positively about any member of staff who responded to them in a caring or empathetic way. These people and their actions were remembered with clarity and described with great warmth' (p.17). It might be assumed that such response could impact on the bereavement process.

A survey of Trusts carried out in 2005 by the Department of Health (a repeat of a 2001 survey) indicated that improvements to bereavement care were happening but there were still considerable gaps. The main

conclusions were for someone to be in charge of bereavement services at Trust level, a desire to have national guidelines, an urgent need for information packs in a variety of languages, a need for dedicated rooms and greater consistency in approach through 'training more (if not all) hospital staff in basic bereavement awareness and communication skills' (p5).

Policies and protocols received from four health boards indicate that they recognise the need to provide local guidance in this area of care. There is a variety of approaches from a large guideline type document, that talks through the care for dying and bereaved, to care pathways that identify the appropriate steps to be taken at each stage of the patient and bereaved journey.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Acute, Hospital Care		
Systematic or systematic type review		
Literature or literature type review	Edwards and Shaw (1998), Kent and McDowell (2004)	2
Experimental/ RCT	Robinson et al (1998)	1
Case Control/ Cohort		
Observational (no comparison group)	Adamowski et al (1993), Cuthbertson et al (2000), Ellison and Ptacek (2002), Ferris et al (1998), Granger et al (1995), Hallgrimsdottir (2004), Li et al (2002), Merlevede (2004), Peters and Lewin (1994), Ping et al (2002), Redinburgh et al (2003), Rogers (2000), Tye (1996)	13
Mixed methods	Billings and Kolton (1999)	1
Qualitative	Del Vecchio Good (2004), Lloyd Richards and Rees (1996), Lopez Socorro et al (2001), Olsson (1997), Street et al (2004), Tunnicliffe and Briggs (1997), Wakefield (2000), Warren (2002)	8
Opinion/text	Edlich and Kubler-Ross (1992), Fauri et al (2000), Haas (2003), Jastremski (1998), Marrow (1996), Silvey (1990), Williams et al (2003)	7
Books, Book Chapters, Reports etc and pre 1990	Doka (1989), Resuscitation Council (UK) (1996), RCN (2002) RCN/BAA&EM (1995), Intensive Care Society Guidelines for Bereavement Care (1998), Department of Social Services – What to do after a death. Department of Health (2003) Department of Health- Consultation Document on Bereavement (2005).	8
TOTAL		40

Key Messages in Acute, Hospital Care

Health care professionals identify the need for education and support. However, different professional groups may have different educational and support needs, related to bereavement and bereavement care particularly doctors and nurses working in hospital settings.

There is a need to ensure appropriate physical resources, irrespective of hospital setting but particularly in settings where resuscitation and acute/unexpected death may occur (A&E, ICU,CCU etc).

The choice of witnessing resuscitation has been identified as potentially helpful and not detrimental to bereavement, in addition enabling and accompanying relatives to view the body is also helpful.

The provision of all forms of information and services should be identified as important, appropriate and of high quality.

Whilst there is no evidence of the effectiveness of follow up from acute care/hospital settings it would appear to offer an opportunity for relatives to seek answers to questions surrounding the death and also for health care professionals to receive feedback on the provision of care at the time of death.

Hospitals may benefit from having an individual 'in charge' of bereavement services in conjunction with national guidance.

A palliative care approach/standards might be adopted across all areas of a hospital, where appropriate, to enhance consistency of care for the dying and bereaved.

Chapter 16: Cancer and Palliative Care

A relatively large number of articles were found referring to bereavement following a cancer diagnosis and palliative care. Although palliative care is applicable for a myriad of diseases and conditions most of the literature was related solely to cancer. Only three randomised controlled trials were included and no systematic reviews were found, although the broader Centre for Advancement of Health (2003) is drawn upon. Four non-systematic literature reviews and a report of five in-depth case studies of five hospices in England were included. Both qualitative and quantitative approaches have been used in bereavement research associated with cancer and palliative care. Several text and opinion pieces have also been included. Most of the papers were low level evidence mainly levels 3 and 4.

Bereavement Services

The need for supportive bereavement services appears to be generally recognised as an integral part of palliative care provision (Payne 2002). Several surveys have attempted to identify the nature and extent of bereavement services provided by hospices and specialist palliative care teams, mainly in the UK and USA but also in New Zealand, and Japan (Field et al 2005; Payne and Relf 1994; Foliart et al 2001; Matsushima et al 2002; Payne 2002; Demmer 2003; Field et al 2004). Wrenn (2001) compares the services and support of an American Hospice with the situation in the Netherlands and highlights specific issues related to euthanasia.

One study conducted in Australia and New Zealand focused specifically on bereavement services for families after the death of a child (deCinque et al 2004). Beardsmore and Fitzmaurice (2002) also provide a description of care provided to bereaved families following the death of a child in one centre in England. Irrespective of the country the main elements of bereavement services offered were the same. Not all hospices provided all the services identified. Services most commonly provided in the UK

were one-to-one support (e.g. befriending, counselling) and telephone support (Field et al 2004). Other services offered included:

- referral to other agencies
- memorial, remembrance or anniversary services
- written information and advice
- support groups
- drop in support.

School support/counselling, medical debriefing and sibling camps were additional bereavement services provided in Australia and New Zealand for families following death of a child (deCinque et al 2004). Bereavement camps for children were also provided by one hospice in California (Foliat et al 2001).

A variety of personnel are involved in delivering bereavement services, although in the UK the largest group is nurses (Field et al 2004). Other personnel involved include religious workers, social workers, doctors, psychologists, administrative and clerical staff, therapists and psychiatrists. Bouton (1996) underlines the importance of a coordinated, multidisciplinary approach, with professionals, volunteers and lay people working together. However, small numbers of people tend to be involved in bereavement services, typically 2-3 paid staff are assisted by 11-12 volunteers (Field et al 2004). Most staff (paid and volunteers) involved in bereavement support activities are employed on part-time basis (Field et al 2004).

Internationally, volunteers play a major role in bereavement support services and tend to be involved in the majority of services (Relf 1998; Foliat et al 2001; Matsushima et al 2002; Payne 2001; Payne 2002; Field et al 2004). Volunteers can help normalise the grief process (Relf 1998) and are also viewed as a cost-effective means of supporting the bereaved (Payne 2002; Field et al 2005). However, some concerns have been raised about whether the cost-effectiveness of volunteers could potentially be exploited (Payne 2002) particularly as most volunteers are women

(Payne 2002; Field et al 2005) and many are over 60 years of age (Payne 2002; Field et al 2005).

Qualifications and training of both health care professionals and volunteers involved in bereavement care varies, as does the duration of programmes. In both the UK and USA the majority of bereavement staff received specialist bereavement training (Demmer 2003; Field et al 2004). However, in the UK this is more likely to be provided if individuals are involved in services provided by an in-patient unit (Field 2004).

Supervision is perceived as important for those involved in providing bereavement care. Although the majority of bereavement staff receive supervision not all do (Field et al 2004) and different arrangements also exist for the supervision of volunteers: some are supported by hospice staff, while others, have to seek outside supervision. Some hospices pay for external supervision whereas some volunteers are expected to fund themselves (Field et al 2005). One study conducted in New Zealand reported that approximately 50% of volunteers found the work emotionally distressing, although opportunities for debriefing through supervision were not always utilised (Payne 2002).

Cultural diversity does not appear to be well addressed in the provision of bereavement services. For example, there appear to be few volunteers from ethnic minority backgrounds (Payne 2001; Payne 2002). Spruyt (1999) highlighted that there is a lack of bereavement support for Bangladeshi carers. As this community commonly use children as interpreters it is suggested that bereaved children of this and other ethnic minorities may be at particular risk of complicated grief.

Inevitably time constraints and lack of staff have been identified as barriers to providing bereavement care (Demmer 2003; Field et al 2004). The number of staff involved in bereavement services have declined since 1986 (Field et al 2004). Field et al (2005) also report that increasing demands on specialist palliative care community nurses impacted negatively on bereavement support work which was continually deferred because of other priorities. Time and staffing constraints highlight the need to ensure that bereavement services are targeted at those most at

risk of developing mental or physical health problems. Numerous assessment tools exist (see below); however, in the UK, less than 50% of hospices have been found to use a formal risk assessment tool (Field et al 2004).

Little information exists about the evidence base for hospice bereavement services or their impact on bereavement outcome. However, in-depth case studies of five hospices in England did reveal that the majority of bereaved people were satisfied with the support they received from hospices (Field et al 2005). This report also found the successful delivery of support groups problematic as it frequently becomes difficult for new members to join. Bereavement support models and the skills required to facilitate bereavement support groups are outlined by Lorenz (1998). However, facilitated support groups have been described as resource intensive and may not be cost effective (Field et al 2005). Formal processes for enabling the bereaved to feed back on the services they receive are recommended (Field et al 2004). NICE (2004) also highlights the need for evaluative research to determine the cost effectiveness of bereavement support services.

Bereavement services tend to be confined to those who have accessed hospice or specialist palliative care services while the deceased was alive. Bereavement services for cancer patients who had not accessed hospice or specialist palliative care appear to be lacking. NICE (2004) indicate that provision of bereavement services is fragmented and often funded by the voluntary sector, although some recent attempts to develop bereavement services in English acute hospital Trusts are reported by Field et al (2005). Lack of contact between bereaved families and professionals may result in support needs not being identified (NICE 2004).

NICE (2004) recommend a three component model of bereavement support is implemented in all cancer networks in England and Wales:

Component 1	Component 2	Component 3
Recognises that grief is normal following the death of a loved one and most support will be provided by family and friends. All bereaved individuals should be offered information about the bereavement experience and how to access different forms of support regardless of place of death or services accessed before death. Health care professionals involved in end of life care should assess the coping abilities, available support and needs of individuals and families in preparation for bereavement.	Offers more formal opportunities to reflect on the bereavement experience and may involve volunteers in preference to health care professionals. Processes should be in place to ensure those with complicated grief reactions are referred to the appropriate professionals.	Is for the small number of people who will require specialist bereavement support including mental health services, psychological support including specialist counselling services.

Protocol development is recommended to engage proactively, particularly with those at risk of complications. Follow-up telephone calls and letters approximately eight weeks following death are suggested.

Assessment and Intervention

Whilst there seems to be a general assumption that bereavement care is part of cancer and palliative care services, it is less clear how assessments for this care should be made and what interventions are most effective. One of the problems with making assessments of people who are bereaved is the wide range and variety of measures that have been used. These measures and scales may not necessarily be applicable in the clinical area in terms of directing care, due to their complexity and time consuming nature. Some of these issues have already been raised in the section on bereavement services and are added to here. A more complete overview of the literature in the field of interventions is provided in a separate section (Chapter 12).

Throughout this review studies have been appraised which use a variety of measures and scales to assess the experience of bereavement. Some of these measures are specific to bereavement, whilst others, for mental wellbeing and illness are also used. In this review one paper, specifically related to palliative care: the 10-Mile Mourning Bridge (Huber and Bryant 1996). Huber and Bryant (1996) believe that accurate assessments of where people are in their grieving process will help deliver timely interventions, particularly where people have unresolved grief. The 10-Mile Mourning Bridge is a 0-10 visual analogue scale that Huber and Bryant compared to the Brief Symptom Inventory (a scale used to measure psychosocial symptoms, some of which may be displayed by grieving people). The participants (74 post-test) in the study attended a hospice bereavement programme, 'Living Through Grief', facilitated by a counsellor. The two scales showed consistency in eight of the nine clinical states, including depression, anxiety, hostility, paranoia, and the authors concluded that the 10-Mile Mourning Bridge could be used to assess where people are in their grieving process. The scale is a relatively simple instrument which could perhaps be a useful assessment tool in clinical practice. However, further research is required to determine the efficacy of the scale.

Kissane et al (1997) looked at family coping following the death of a loved one in a palliative care setting and found it to be the most consistent correlate of bereavement outcome (see also *Family* Chapter 6). Family Focused Grief Therapy has since been developed by Kissane et al (2003) beginning in the palliative phase of illness. It is thought to be of particular benefit to those who are shown to be at high risk of poor adaptation. Kissane (2003) describe this model as offering, 'a new emphasis on shared family grieving as a pathway to adjusting to death'. The delivery of this programme, by trained counsellors, involves 'classifying' families as to how they function by screening with the Family Relationships Index (FRI). Support is offered to those who appear most at risk of problems and would typically involve four to eight sessions. Kissane questions whether the palliative care field is ready to take on such a structured family orientated approach as clearly there would be many service, resource and professional issues raised.

In a study looking at the impact of individual psychosocial intervention on the use of inpatient and outpatient health care services by bereaved spouses, Connor and McMaster (1996) conclude that there may be an association between the two. They looked at hospital use in the year before and after death. A non-random sample of 354 widowed spouses, from a medical centre were assigned to three intervention groups: nonintervention, limited intervention and extensive intervention. The extensive intervention group was comprised of widows whose husbands had received hospice services, and consequently received more input prior to the death, at the time of the death and in the initial stages of bereavement. It appeared that the extensive intervention group did make less use of services in the first year of bereavement.

Conceptually, the assumption that hospital usage is an indicator of health *per se* can be questioned. In addition, the fact that different modes of death and care situations prior to death were evident in the sample may have influenced these results. However, the authors also suggest that the model of hospice care where there is more emphasis on care at the end of life and follow up in bereavement could also be applied to other situations.

A recurring theme in the literature is the presumption that 'something should be done' for people who are bereaved, and it is not always clear whose needs are being met. Kaunonen et al (2000a) describes setting up a system to phone family members after the death of a relative on an Oncology ward in Finland. No evidence of effectiveness in terms of enhanced bereavement outcomes is apparent.

However, in their review of the role of bereavement support groups in oncology services, Lorenz (1998), states that not providing support has medical and emotional implications for surviving family members. The types of support groups discussed are:

- time limited model (6-8 weeks limit)
- ongoing support groups (weekly)
- monthly support groups
- self Help groups.

A number of benefits and pitfalls are described depending on leadership issues, referral criteria, composition of the groups and dynamics within the groups.

At an individual level the issue of coping and self-efficacy (in widows) was investigated (Benight et al 2001). They developed a measure of bereavement coping self-efficacy (BCSE) which when administered alongside a variety of other measures supported the hypothesis that BCSE was a predictor of emotional distress, psychological well-being, spiritual well-being and physical health perceptions. This links in with other psychological work looking at human resilience referred to in other sections by Bonanno and colleagues.

In conclusion, there is general agreement on the need for assessment of individuals and families in the bereavement period, particularly to identify those at most risk. However, there is a lack of consensus on how this should be carried out, by whom, and at what time.

Experience of Bereavement

Field et al (2005) comment on the importance of pre-bereavement care on the bereavement experience. Due to the scale of this review process, a conscious decision was made to exclude areas of pre-bereavement from this review if they did not affect the bereavement period. There may therefore be important influences on the bereavement experience that are not covered.

Several studies specifically explored the experience of close family members following the death of someone from cancer. Their focus was largely the physical and emotional effects of loss and in some cases comparisons of different family members to determine if bereavement reactions differed. Populations under investigation included mothers, spouses and daughter caregivers.

Other studies focused on whether particular variables may contribute to increased distress and grief. Gilbar (1999) found that gender, age category and past grief experience were significant variables. However, there are indications that emotions in bereavement are not all negative and that in particular positive emotions can arise when individuals feel they have done as much as they possibly could in the dying phase (Davies et al 1998; Koop and Strang 2003).

The largest study reviewed was a Swedish study examining the long term physical, psychological and socioeconomic effects of widowhood following a husband's death from prostate or bladder cancer, compared with women who lived with their husband (Valdimarsdottir et al 2003). Using measures that the authors developed and other scales, they found that bereaved widows are more likely to suffer from psychological distress, sleep disturbances and diabetes than women living with their husband. Dissatisfaction with their economic situation was also mentioned as well as feeling unappreciated outside of the home. Changes in income (usually a decrease) have been reported in other studies and it has been suggested that this is an area that deserves attention in the pre-bereavement period (Wyatt 1999) as it can significantly affect the bereaved.

The issue of place of death and caring for dying family members at home and its influence upon the experience of bereavement was touched upon by Davies et al (1998) and Koop and Strang (2003). This work is also linked to McCorkle et al's 1998 study on the type of nursing care provided and how it influences the experience of bereavement. McCorkle et al (1998) linked specific models of nursing care to bereavement outcomes and concluded that specialized oncology nursing services for people with lung cancer may be linked to reduced psychological distress in the bereavement period.

Davies et al (1998) took a cross cultural view of the experiences of mothers following the death of a child from cancer. They interviewed mothers (21 in total) in Canada, Norway, Greece, Hong Kong and the USA, and transcribed, coded (and translated in some cases) the mother's responses. In this study no cultural differences were noted and the mothers recounting of their experiences were more similar than different.

The mothers' accounts focused on the care their child had received, which was mostly at home, as well as their emotional and physical responses to loss. The devastation caused by the loss of a child was summed up in two quotes from mothers as 'my life went to pieces' and 'the fear of never finding joy again'. The most comforting and positive aspects experienced in the bereavement period for these mothers were the valuable support of family, friends and professionals and the knowledge that they had been totally involved in the care of their child. Koop and Strang (2003) similarly reported positive emotions in adult carers who had felt they had accomplished a great deal by keeping their relative at home to die.

Jacob (1996) used interviews to explore the grief experiences of older women, and developed 'core concepts' from the narratives. These were summarised as 'being aware', 'experiencing distress', 'supporting', 'coping', and 'facing new realities'. They suggest such exploratory work could be used to develop intervention programmes.

The effect of different care giving relationships was looked at by Bernard and Guarnaccia (2002), by comparing husbands (126) with adult daughters (87). Data was used from the National Hospice Study carried

out in the early 1980s and aspects of general grief experience and despair were compared between the two groups. Daughter caregivers who lived with their mother had greater despair than daughter caregivers who did not live in the same household; otherwise there were no significant differences. The data for this study was taken from over 20 years ago and it was not clear exactly how it was extracted which may add uncertainty to these findings.

Factors influencing Bereavement Outcome

The bereavement outcome of families is viewed as an important consideration in cancer and palliative care. Common themes in the literature thought to influence bereavement outcomes are: characteristics of the deceased, characteristics of the bereaved, relationship with the deceased, characteristics of illness, nature and place of death, how prepared for death the bereaved felt, the caregiving experience, family functioning and experience of terminal care. Many of the studies are retrospective with self-selecting small samples.

Characteristics of the Bereaved

Personality traits such as trait anxiety, depression, neuroticism, satisfaction with life and being emotionally fragile have been associated with the perception of emotional burden (Ferrario et al 2004). Females have also been shown to have significantly more psychological distress following bereavement than males (Gilbar & Ben-Hur 2002; Ferrario et al 2004). Age has also been implicated as a predictor of distress although results are somewhat contradictory. Poorer psychological and physical health have been associated with older carers and increasing age (Brazil et al 2002; Ferrario et al 2004). Conversely, caregivers of younger patients have reported significantly higher levels of depressive symptoms than caregivers of older patients (Wyatt et al 1999). Poorer physical health is also associated with poorer mental health during bereavement (Brazil et al 2002).

Bereavement maladjustment has also been associated with baseline personality traits and the perception of caregiver problems (Ferrario et al 2004). Experience of childhood separation from parents, past

bereavement and individual coping styles of accepting or assuming responsibility for circumstances or the avoidance of emotion are all cited as predictors of bereavement distress (Kelly et al 1999).

Individual perceptions of own coping abilities have also been suggested as a predictor of bereavement outcome with those who rate their own abilities higher experiencing less emotional distress and improved psychological, physical and spiritual well-being (Benight et al 2001).

Relationship with the Deceased

Being married to the deceased has been found to be highly predictive of bereavement maladjustment 12 months after death in an Italian study (Ferrario et al 2004). Lower levels of intimacy have also been shown to increase the likelihood of bereavement distress (Kelly et al 1999).

Greater severity of illness has been shown to be a predictor of bereavement distress (Kelly et al 1999). One large Israeli study comparing bereaved parents whose adult sons had been killed either from war or by accident, to those whose sons had died from cancer, found bereavement had no significant effect on cancer incidence (Levav et al 2000). This study provides some weak evidence suggesting an increase in specific cancers (lymphoid/haemopoietic and melanomas in both bereaved groups and an increase in respiratory cancer in males and uterine and ovarian cancers in the accident bereaved group). For cancers diagnosed before bereavement, parents in the war bereaved group had a significantly higher risk of dying than controls. However, risk behaviours are not considered as possible confounders therefore cause and effect cannot be established. The literature review carried out by the Center for the Advancement of Health (2003) suggested that research findings indicating a relationship between bereavement and mortality and morbidity are inconclusive due to a variety of confounding methodological issues.

Care-giving Experience

Care-giving has emotional and physical costs for carers and may alter their social involvement and employment. Care-givers who reported that care-giving interrupted their usual activities have shown a decline in physical health, whilst those who perceived insufficient family support experienced poorer mental health (Brazil et al 2002). In a further study 30% of employed care-givers stopped working temporarily and 10% stopped altogether (Ferrario et al 2004). Death may actually decrease caregiver burden and therefore does not increase levels of distress (Centre for the Advancement of Health 2003).

Experience of terminal care

The effects of terminal care on bereavement outcomes have shown contradictory findings. The one randomised control trial in this area was conducted in the USA and compared the effects, on the psychological distress of the bereaved, of a specialised oncology home care programme with a standard home care programme and an office care programme (McCorkle et al 1998). Lower levels of distress were found to be sustained over 13 months for bereaved carers whose relative had received the oncology home care programme.

Receipt of hospice care has also been associated with lower mortality of surviving elderly spouses (less than 65 years old) during bereavement and contributing to the adjustment process after bereavement (Kramer 1997, Christakis & Iwashyna 2003). The specific components of hospice care contributing to this outcome remain unclear.

Other studies have found no difference between hospice and standard care (USA) (Rogow-O'Brien et al 2000) and between Hospital at Home and standard care (UK) (Grande et al 2004). However, Rogow-O'Brien et al (2000) did find that individuals who accessed hospice care reported greater positive emotional wellbeing if they perceived their relatives death to be painful and greater overall positive emotional wellbeing than those who received conventional care.

Perceived adequacy of care and immediate bereavement response have also been found to be associated with higher distress levels but were not significant six months post bereavement (Grande et al 2004). The ability to face and accept the reality of their husband's death during their terminal illness has been shown to be significantly higher in women whose husbands had received hospice services, and has been found to be strongly associated with better post bereavement adjustment (Kramer 1997).

Social Support and Family Functioning

Low levels of social support have been shown to be predictive of short term bereavement distress (Kelly et al 1999). Kissane et al (1997; 2003) contend that the nature of family support and functioning are key aspects of social support in influencing bereavement outcome and suggest that family units rather than individuals should be assessed for the risk of psychological morbidity after bereavement. The Centre for Advancement of Health (2003) also indicate that social and emotional support may help to buffer bereavement distress.

Preparation for and place of death

Lack of preparation for death is suggested as an important risk factor for identifying people at greater risk of psychiatric complications after the death of a loved one (Centre for Advancement of Health 2003). Support of family and friends is perceived by individuals to help people feel more prepared for death (Barry and Prigerson 2002).

Having information of their husband's impending death from cancer 24 hours or less before death has also been associated with higher risk of widows experiencing death as shocking, being bitter about the health care provided, and difficulties in coming to terms with their loss (Valdimarsdóttir et al 2004).

Death at home is associated with significantly better early bereavement response but was not significant six months post bereavement (Grande et al 2004). Home death has also been associated with better mental health of the caregiver (Brazil et al 2002). Other researchers suggest that dying

at home may increase psychological distress for relatives (Addington-Hall and Karlsen 2000).

Bereaved parents whose child died in hospital show significantly higher levels of depression with fathers also showing higher levels of anxiety and stress than those whose child died at home (Goodenough et al 2004). Parental psychological distress has also been shown to be increased for parents whose child died in hospital following stem cell transplant (Drew et al 2005). Parents whose child had received stem cell transplant also showed higher levels of depression, anxiety and distress than those parents whose dead child had not received such treatment.

Beardsmore and Fitzmaurice (2002) emphasise the importance of choice in the place of death for children dying of cancer and suggest that place of death should be revisited regularly to ensure families remain comfortable with their choice.

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Cancer and Palliative Care		
Systematic or systematic type review	Centre for Advancement of Health (2003)	1
Literature or literature type review	Beardsmore and Fitzmaurice (2002), Wrenn (2001), Lorenz (1998)	3
Experimental/ RCT	Connor and McMaster (1996), McCorkle et al (1998), Ringdal et al (2001)	3
Case Control/ Cohort	Bernard and Guarnaccia (2002), Christakis and Iwashyna (2003), Drew et al (2005), Kramer (1997), Levav et al (2000), Rogow-O'Brien et al (2000)	6
Observational (no comparison group)	Addington-Hall and Karlsen (2000), Benight et al (2001), Brazil et al (2002), Davies et al (1998), DeCinque et al (2004), Demmer (2003), Ferrario et al (2004), Field et al (2004), Foliart et al (2001), Gilbar (1999), Gilbar and Ben-Zur (2002), Goodenough et al (2004), Huber and Bryant (1996), Kaunonen et al (2000a), Kelly et al (1999), Kissane et al (1997), Kissane et al (2003), Matsushima et al (2002), Payne and Relf (1994), Vladimarsdottir et al (2003), Wyatt et al (1999)	21
Mixed methods	Barry and Prigerson (2002), Payne (2001), Payne (2002)	3
Qualitative	Grande et al (2004), Jacob (1996), Koop and Strang (2003), Spruyt (1999)	4
Opinion/text	Bouton (1996), Kissane (2003), Relf (1998)	3
Books, Book Chapters, Reports etc and pre 1990	Field et al (2005), NICE (2004)	2
TOTAL		46

Key Messages in Cancer and Palliative Care

The families of those who access hospice and specialist palliative care services generally have better access to bereavement care both before and after death. Bereavement care should be available to everyone.

Implementing NICE guidelines for palliative care should improve bereavement services for all families of those dying from cancer but may increase inequity to those dying from other diseases. Standards/protocols for bereavement care are required for all settings.

Cultural diversity needs to be addressed in bereavement services in palliative care.

Since uncomplicated grief seldom requires medical treatment it is prejudicial to treat it as a medical diagnosis. Most people will cope with their bereavement with the support of friends and family.

As multiple factors may influence bereavement it is essential to undertake assessment of risk. There is a need to identify those who are less likely to cope and at risk of complicated grief. Formal assessment tools require to be used to facilitate this process.

All staff involved in bereavement care require appropriate education, training and supervision.

Time and staff constraints are obstacles to providing bereavement services and support and specialist practitioners should be enabled to focus.

Chapter 17: Education of Health and Social Care professionals

The Centre for Advancement of Health (CAH) (2003) literature review states that there is little evidence available on education and training for health care professionals. Questions such as whether it is adequate, what it should cover, when it should be done, and whether it will make a difference remain unanswered. However, this current review identified a relatively small amount of literature, much of it at the lower evidence levels, which addresses some of these questions.

The CAH (2003) review also reports that for health care professionals longer periods of contact with the bereaved tends to increase their own feelings of grief. Therefore it might be assumed that both education and support should be available for health care professionals. The CAH review (2003) does indicate that health care workers who receive education on death and dying are more comfortable in dealing with grief and bereavement, although this does not necessarily mean they are less stressed.

Most professional groups have identified a need for further educational provision. For example: Johnston et al (2001) in GPs and Community Nurses; Barclay et al (2003) in GPs; McAteer and Murray (2003) in physiotherapists; Field and Wee (2002) in medical students. Kramer (1998) identifies the need for social workers to have appropriate education as they are also highly likely to deal with loss and grief. In addition, Wass (2003) identifies the need for paramedics to undertake education as they are often faced with death, dying and bereavement. Even US dental schools (Johnson and Henry, 1996) are now more likely to include some education on death, dying and bereavement in the undergraduate programme.

Provision of Education

One of the key factors identified for education is the need to ensure that the course or programme addresses the experiences and needs of the participants (Wass 2003; Douglas 2002; Gould 1994; International Work Group on Death, Dying and Bereavement 1991; Papadatou 1997). Specific groups, within the broad range of health and social care professionals, may also require specific training/education. Papadatou (1997) seeks to highlight specific needs in respect of children's deaths. Ng and Li (2003) indicate some uncertainty about educational needs from those working in learning disability settings, and DiMarco (2002) and Thomas and Kohner (1994) for those who deal with perinatal deaths and bereavement.

Wass (2003) contends that the inadequacy of educational preparation threatens the quality of bereavement interventions and suggests that consensus on the knowledge, skills and personal understanding required is necessary. As a first step, development of principles and guidelines are proposed, although referring primarily to grief counsellors this has implications for all health care professionals.

The International Work Group on Death, Dying and Bereavement (1991) supports the principle that any education should be interdisciplinary in nature, examining the different professional perspectives whilst seeking similarities. Doorenbos et al (2003) endorses this perspective.

Several articles describe specific educational initiatives (Thomas and Kohner 1994; Matzo et al 2002; Papadatou 1997; Douglas 2002; Di Marco et al 2002; McAteer and Murray 2003). Particular approaches to teaching have been described in the literature: use of humanities, such as literature, poetry, drama, music, art (McAteer and Murray 2003), metaphor (Gould 1994), volunteer parents (Thomas and Kohner 1994), illustrative case histories (Matzo et al 2002), and videos (Thomas and Kohner 1994; Matzo et al 2002). Only anecdotal evidence exists to support the effectiveness of any of these approaches.

Curriculum Content and Teaching

Curriculum content in most health related programmes has increased and the approach to teaching death, dying and bereavement has positively changed in UK medical schools since the 1980s but is still often associated with palliative care education (Field and Wee 2002) and viewed as challenging (Fuller 1999).

Nursing schools in the USA have shown similar curriculum change and updating but often draw on bereavement models that may be inappropriate in all settings, or outdated (Coolican et al 1994). However, there is a paucity of literature relating to the situation in the UK. A national US programme for nurses, End-of-Life Nursing Education Consortium (ELNEC)¹⁵, was developed to assist nurses in dealing with death, dying and bereavement and evaluated by Ferrell et al (2005). The cascade process used, initiated change at faculty level that appeared to impact on educational provision (a similar medical programme had also been developed). Significant improvements in students' knowledge were demonstrated in six out of nine modules. However, no improvement in knowledge was reported for the grief and loss module. Grief and loss was also unique in being the only module where mastery improvement was not significant. The authors (Ferrell et al 2005) suggest this is because responses may have been influenced more by personal experience than by knowledge.

Exploring the personal dimension of bereavement and experiential learning as crucial components of education is also highlighted in several other educational initiatives (Thomas and Kohner 1994; Gould 1994; Papadatou 1997; Matzo et al 2002; McAteer and Murray 2003; Wass 2003). This is an interesting perspective as it has implications for future educational provision and should be investigated further.

¹⁵ <http://www.aacn.nche.edu/ELNEC/about.htm>

Some on-line programmes exist that may help volunteers and practitioners.¹⁶ The Department of Health, possibly in response to the issues surrounding organ retention at Alder Hey, have funded a range of initiatives aimed at developing and implementing bereavement training including some on-line developments.¹⁷ These initiatives appear to cover a range of perspectives, from that related to post mortem guidelines to general grief and bereavement courses in a variety of local settings. No reports are yet available from these projects. We are also aware that courses, such as that run by the Open University have been established for some time, however, we found no literature that described or evaluated this programme. A table detailing the content of those courses identified above is seen in Table 3 overleaf.

¹⁶ <http://itrs.scu.edu/fow/>

¹⁷ http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Bereavement/BereavementGeneralInformation/BereavementGeneralArticle/fs/en?CONTENT_ID=4094042&chk=LMUfBn

Table 3: Identified educational programmes to assist volunteers and practitioners

Curriculum Topics	Type of course	Teaching Strategies	Authors
Grief theory, phases of bereavement, role of clergy, cultural and religious beliefs and perinatal loss, children's responses to perinatal loss, losses in early pregnancy, strategies for care, parent reflections.	1 day conference – perinatal loss	Lecture, small group presentations, role play case presentations, panel presentations.	DiMarco et al 2002
Pregnancy and parenting tasks, grief theory, grief counselling, parent panel, miscarriage, ectopic pregnancy and infertility, cultural and religious perspectives, strategies for care, communication skills, children and death, role of the funeral director, parent support groups, role of the clergy, physician perspective, telephone follow up, getting started, care for the caregiver.	3 day conference – perinatal loss	Lecture, small group presentations, role play case presentations, panel presentations.	DiMarco et al 2002
Attitudes towards death and dying, symptom relief in advanced terminal disease, analgesics for chronic pain, analgesics for cancer pain, communication with family members of dying patients, grief and bereavement, psychological aspects of dying, social contexts of dying, euthanasia, communication with dying patients, the experience of dying, certification of death, advanced directives, end of life hydration, religious and cultural aspects of dying, end of life nutrition, relating to patients with AIDS, neonatal issues, other physical therapy.	Undergraduate medical education – themes across courses in UK medical schools	Seminar/small group discussion, role play, clinical case discussions, hospice visit, lecture, video/film, use of dying patient to address class, simulated patients.	Field & Wee 2002

<p>Nursing care at end of life, pain, symptom management, , ethical/legal issues, communication, grief, loss, bereavement, quality care at the end of life, death.</p> <p>Patient, family & nurse, nurses role, the grief process, loss, mourning, grief and bereavement, cultural considerations, anticipatory grief, normal grief, complicated grief, risk factors, complicated reactions including disenfranchised grief, children's grief, stages and tasks of grief, factors affecting grief process, grief assessment, bereavement interventions, grief interventions, completion of bereavement process.</p>	<p>End of Life Nursing Education Consortium Undergraduate Faculty Training Program</p>	<p>Lecture, use of literature, exemplars and case studies, role modelling, experiential learning, cumulative loss exercises, reflection, facilitated discussion.</p>	<p>Ferrell et al 2005</p> <p>Matzo et al 2003</p>
<p>Paediatric hospice philosophy and principles of care, research and applications, chronic and life-threatening illness in childhood, factors affecting individual and family coping and adjustment, symptom control and management during terminal phase, psychological and spiritual care of the dying child and support of family, symbolic and creative methods of interaction with dying and bereaved children, grief process (parental and sibling bereavement) cultural aspects, impact of caring for a dying child and grieving families on professionals, stress management and prevention of burnout, ethical issues, developmental psychology, crisis intervention, counselling skills, systematic theory and applications to families facing illness and death.</p>	<p>600 hour training programme on home-based palliative care for children dying of cancer</p>	<p>Class attendance, supervised clinical practice, participations in a sensitivity group, journal keeping, lectures, discussions, case presentations, simulations, role play.</p>	<p>Papadatou 1997</p>

Culture

A small amount of education related literature highlighted the need to ensure inclusion of cultural factors in death and dying education. Matzo et al (2002) discuss cultural considerations in the context of the ELNEC programme, outlined above. They identify culture as including ethnicity, race, gender, age, differing abilities, sexual orientation, religion and spirituality, socioeconomic factors, and place of residency. In addition cultural competence is seen as a key factor. Dowd et al (1998) perceive the need for a more 'relevant' cultural model for death, dying and grief education that deals with communication, space, social organisation, time, environmental control and biological variation.

Hunt (2002) outlines the use of a 3x3 bereavement table to assist volunteers and professionals of different cultures, races and faiths to identify key areas of bereavement across the time span. Such a tool may be a helpful aid to teachers. Doorenbos et al (2003) argues for the inclusion of anthropological, ethical and sociological content into end-of-life programmes. She argues that students need to have their awareness raised of impact of culture on death, dying and grief (anthropology), how ethical and moral factors affect any care and the context of spiritual and religious factors (sociology).

Evidence Reviewed

The following table provides an overview of the type of evidence reviewed for this chapter.

Type of Evidence	Papers	Total
Education and Professional Development Papers		
Systematic or systematic type review	Centre for Advancement of Health (2003)	1
Literature or literature type review	Papadatou (1997)	1
Experimental/RCT		0
Case Control/ Cohort	Kramer (1998)	1
Observational (no comparison group)	Barclay et al (2003), Coolican MB (1994), DiMarco et al (2002), Ferrell et al (2005), Field and Wee (2002), Johnson and Henry (1996), Johnston et al (2001), Ng and Li (2003)	8
Mixed method		0
Qualitative		0
Opinion/text	Doorenbos et al (2003), Douglas (2002), Gould (1994), Dowd et al (1998), Fuller (1999), Hunt J (2002), International Work Group on Death Dying and Bereavement (1991), Matzo et al (2002), McAteer and Murray (2003), Thomas and Kohner (1994), Wass (2003)	11
Books, book chapters, reports etc	End-of-life Nursing Education Consortium (ELNEC)	1
TOTAL		23

Key messages in Education and Professional Development

There appears to be a need for increased education in both undergraduate and postgraduate education for health and social care professionals. Such education should always include the examination of personal loss, and support students therein. It may be multi-professional and consider appropriate cultural values and beliefs.

Educational courses need to consider a wide range of clinical and social contexts as these may require specific/targeted input.

As with other educational provision there is lack of evidence demonstrating the impact of education on practice.

There is an acknowledged challenge to including death, dying and bereavement into educational programmes that could be enhanced through a nationally driven initiative (for example through development of principles/guidelines/ curriculum/'cascadeable' programme), rather than local, variable provision.

Including bereavement care as an integral part of palliative care education may be appropriate in the future with current trends to encompass care of all end stage long term disease under the palliative care umbrella rather than concentrating solely on those dying from cancer.

SECTION 5: Conclusions

This final section draws together and concludes the key messages identified in the preceding chapters. The first chapter (18) deals with issues of research which surfaced throughout the review. Although such issues, in relation to bereavement, are not new, we considered them worthy of reporting to reinforce the need for greater consideration to be given to research and also its reporting. The overall key messages are mapped out in Chapter 19, these have also been adapted to form an executive summary to accompany this review document. The final chapter (20) seeks to provide some concluding remarks on the entire review, which in itself is not without challenge.

Chapter 18: Research Issues

Research surrounding death, dying and bereavement is fraught with difficulties that relate to the sensitivity surrounding the topic and the many variables that will influence the outcomes (Dyregov 1990). It may be considered that some key problems exist:

- absence of control groups in most quantitative studies
- many have cross sectional designs
- potential reporting bias across all research and literature
- non standardised measures of grief and use of different scales
- difficulties with operational definitions eg spirituality, types of grief, counselling
- sample sizes are usually small and bias in sampling may occur due to recruitment difficulties, self selection.
- response and drop out rates are underreported
- ethical issues surrounding access, including blocking by professional groups and ethic committees.
- confounding variables are often not identified or addressed
- memory bias as many studies are retrospective, sometimes up to 20 years
- self report of most research
- potential for researchers to withdraw/withhold questions due to the potential for the research being viewed as therapy
- for the qualitative papers there is poor reporting of methodology/method.

As 'outsiders' to this field we are struck by the myriad of scales and tools that have been developed to measure grief and bereavement and which we did not evaluate but which have been questioned (Tomita and Kitamura

2002). It is not the case that we are suggesting there are too many, as we are aware of tools being valid and sufficiently sensitive to measure what they set out to measure. However, when seeking to review studies where a plethora of scales and inventories have been used and the groups may vary in age, sex, time since the death, economic status etc it is difficult to compare or perform any form of meta analysis due to this heterogeneity. Such meta-analysis could be helpful as bereavement research often has small samples due to problems of recruitment.

As in many areas of research there is discussion related to qualitative versus quantitative approaches. Balk et al (1998) highlight the differentiation between a participant's scoring on the IES (Impact of Events Scale) and her own diary writings indicating different and more severe morbidity. Good quality research of all types or mixed methods seem essential to measure effect and illuminate this field of enquiry.

Stroebe (2004) discusses some of the shortfalls in respect of spirituality/religious research into grief and bereavement. Dyregov (1990) in relation to parental bereavement. Furthermore within any area of bereavement it is probable that the research itself will impact on outcome and thus, potentially, affecting any results.

Parkes (1995) highlights the ethical difficulties of bereavement research and the need to protect the bereaved from 'unscrupulous or potentially harmful intervention' (p173). Alternatively there may be blocking of well designed research by ethics committees and professionals that needs to be addressed. Tissues in both areas may no longer be problematic in the light of recent research governance changes, although the issues Parkes' raises in this context should be carefully considered with this vulnerable group. Conversely, the use of some research methods, such as phenomenological interviews, may actually be of benefit to the bereaved (Dyregov 2004) although this requires a respectful, empathic and informed researcher without time limits. The skill of the researcher is rarely questioned or identified in the bereavement literature but we would now consider that this

is a critical factor at both the level of expertise but also at the personal level (Sque 2000).

Future research needs to consider how it may overcome some of the difficulties encountered, some of which may be problems of reporting as much as problems of the research itself. Development of a specific centre, to undertake research into bereavement in health and social care environments could, we believe, begin to address some of the shortfalls identified. It must also be the case that such a centre would also undertake education and practice based work to address some of the issues raised throughout this review. Thuen and Sandvik (1998) highlight the value of combining bereavement research and practice in one department. A review of specific grief and bereavement services undertaken in Australia, although concerned with different health care structures, highlighted the need to have a more integrated approaches that could be developed through a single entity such as a Centre (Department of Human Services 2004)

The Centre for Advancement of Health (2003) indicate a general issue related to research, namely that 'Research and conceptual work are needed to develop clearer frameworks for understanding the diversity and complexity of grief and bereavement research, both within a larger cultural context and with awareness that normal grief takes many forms' (p.75). They go on to identify a range of other research that relates to health outcomes, the role of health care providers and health care systems in providing care and the efficacy and effectiveness of bereavement and grief interventions. Research that examines the social and educational contexts in addition to those described for health should also be added.

The CAH (2003) report goes on to suggest that research is needed to determine what constitutes best practice, as there are considerable gaps in knowledge related to the ability of health care organisations in particular to support some of the care described in this review.

Key Messages in Research

Rigorous research in many areas of health and social care is needed in relation to bereavement.

Consideration should be given to establishing a 'Centre' (virtual or otherwise) for Bereavement Care in Scotland, which develops research, in conjunction with practice and education and could provide co-ordinated activity and seek to enhance care in Scotland.

Chapter 19: Overall Key Messages from the Reviewed Evidence

Mapping the key messages from the preceding chapters created 13 overall key messages. These are presented below with some broad recommendations for policy and practice.

- **Grief is a normal process.** The response to death by individuals is influenced by a range of factors which need to be understood by health and social care professionals and others.
- **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.** It appears appropriate to develop assessment of risk in all settings.
- **Interventions should be tailored to need.** Specific groups of bereaved appear to benefit most from different forms of intervention e.g. those at most risk, men and women, children, adolescents.
- **Follow up has been identified as important, particularly by the bereaved.** In our current state of knowledge several types of service are possible and attention should be paid to local availability and preferences. Targeting of those most at risk is important.
- **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. This should also include occupational and occupational support services.

- **Cultural and spiritual factors**, including issues of addressing stigma (e.g. in HIVAIDS and suicide), need to be incorporated into all areas of bereavement care and education.
- **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**, for example, this may involve palliative care standards being implemented across all area. Guidelines for specific aspects of care, such as associated anxiety and depression should be developed.
- **Education for health and social care professionals is identified as in need of development.** Multiprofessional, national programmes could be considered, covering both pre and post graduate settings and also volunteer agencies. Education related to death and bereavement should be part of school curricula. The preparation of teachers and organisations for the above needs to be considered.
- **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.**

Chapter 20: Concluding remarks

This review has covered a considerable amount of literature related to death, dying and bereavement. Much of this has been low level evidence, based on perspectives from evidence-based practice, although as we contended in the introduction this does not necessarily equate to a need for no change or action. Whilst there may be some contention related to selection or inclusion of specific evidence, we believe that the key messages developed from our review are consistent with present perspectives on bereavement and bereavement care. Although many reports now include a section on implications and recommendations we considered that concluding remarks provided the appropriate end point for the review. The implications and recommendations are perhaps already implicit in the overall key messages.

However, in seeking to keep to the remit of our review we have paid less attention to some areas related to bereavement, for example management of depression and anxiety, evaluation of grief/bereavement assessment tools and more general work on post-traumatic stress disorder. In addition the inclusion of work on anticipatory grief is often implicit in some of the studies but we have not sought to develop it into a distinct category. Other distinct areas that were identified such as dementia and bereavement and bereavement in prisons were also missed, although they are also important. The above areas would benefit from further specific review and development.

There is, we consider, a large range of evidence (primary, secondary and grey) that relates to the applicability, meaningfulness and feasibility of practice in bereavement and bereavement care. However, the extent of evidence of effectiveness is limited, although as we have argued at the outset, such evidence is not always the most important or useful to organisations and practitioners.

There is, across all areas, an indication of the need for enhanced psychological care provision for the bereaved and also for those professional and volunteers who are engaged in bereavement care. This includes, for the bereaved: the need for appropriate assessment to identify those who are

most vulnerable and at risk, provision of consistent and accurate information, tiered models of care that are linked to competency frameworks and services that are then configured accordingly.

To achieve this there is a need for co-ordination or facilitation of activity within each locality as it is evident that a range of agencies and professionals will need to be involved. However, as far as we are aware there has been no review and assessment of available bereavement services in Scotland to determine this range.

It must finally be acknowledged that bereavement and bereavement care would benefit from an increase in quality of and reporting of, research. This is applicable both to larger experimental studies and to smaller in-depth qualitative studies. Such enhancements could eventually result in more appropriate service provision by statutory and voluntary sectors.

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APPENDIX 1: Appraisal and Extraction Forms

JBI Critical Appraisal Checklist for Systematic Review	
Reviewer	Date
Review details (author, date, title, publisher etc)	
1. Is the review question clearly and explicitly stated?	Yes No Unclear
2. Was the search strategy appropriate?	Yes No Unclear
3. Were the sources of studies adequate?	Yes No Unclear
4. Were the inclusion criteria appropriate for the review question?	Yes No Unclear
5. Were the criteria for appraising studies appropriate?	Yes No Unclear
6. Was critical appraisal conducted by two or more reviewers independently?	Yes No Unclear
7. Were there methods used to minimise error in data extraction?	Yes No Unclear
8. Were the methods used to combine studies appropriate?	Yes No Unclear
9. Were the recommendations supported by the reported data?	Yes No Unclear
10. Were the specific directives for new research appropriate?	Yes No Unclear
Estimate level of evidence and if applicable to Feasibility, Appropriateness, Meaningfulness, or Effectiveness (FAME)	
Comment	

Overall Appraisal Include
 Exclude
 Not sure

Extraction form for systematic reviews/meta analyses	
What types of studies are included in the review (identify all that apply)?	<input type="checkbox"/> RCT <input type="checkbox"/> CCT <input type="checkbox"/> Cohort <input type="checkbox"/> Case-control <input type="checkbox"/> Other (please specify)
Participants and degree of homogeneity between groups	
Setting(s) in which review/studies were carried out.	
<p>How does this review/meta analysis help to answer the key questions: (Summarise the main conclusions of the review and how it relates to the relevant questions. Comment on any particular strengths and weaknesses of the review as a source of evidence for this review)</p> <ol style="list-style-type: none"> 1. What present knowledge and practices are identified as underpinning bereavement care? 2. In what ways are individuals and organisations involved in bereavement care? 3. What is the experience of bereavement care? 4. What interventions are effective in bereavement care? 5. What are the outcomes of bereavement care? 	

JBI Critical Appraisal Checklist for Experimental Studies			
Reviewer	Date		
Author	Year		
Record Number			
	Yes	No	Unclear
1. 1. Was the assignment to treatment groups random?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were participants blinded to treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was allocation to treatment groups concealed from the allocator?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were those assessing outcomes blind to the treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were the control and treatment groups comparable at entry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were groups treated identically other than for the named interventions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Was there adequate follow-up (>80%)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Was appropriate statistical analysis used?.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is this paper related to Feasibility, Appropriateness, Meaningfulness or Effectiveness (or a combination)? (Experimental papers are normally related to Effectiveness issues) What level is this rated at (1-4)?			

Overall Appraisal Include
 Exclude
 Seek further info.
 Comments (Including reasons for exclusion)

JBI Critical Appraisal Checklist for Case Control Studies			
Reviewer	Date		
Author	Year		
Record Number			
	Yes	No	Unclear
1. The cases and controls are comparable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Exclusion/Inclusion criteria are similar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Cases and controls are clearly defined and differentiated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have measures been taken to prevent knowledge of treatment/management influencing cases?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Are the main potential confounders identified and taken into account in the design and analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are you certain that the overall effect is due to the exposure/treatment/management?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is this paper related to Feasibility, Appropriateness, Meaningfulness or Effectiveness (or a combination)?	<input type="checkbox"/> <input type="checkbox"/>		
10. What level is this rated at (1-4)	<input type="checkbox"/> <input type="checkbox"/>		

Overall Appraisal Include
 Exclude
 Seek further info.
 Comments (Including reasons for exclusion)

JBI Critical Appraisal Checklist for Cohort Studies			
Reviewer	Date		
Author	Year		
Record Number			
	Yes	No	Unclear
1. The two groups being studied are comparable?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Exclusion/Inclusion criteria, including sampling, are similar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. All participants, including those who dropped out, are included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The assessment of outcomes is blinded to exposure/treatment/management?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Are the main potential confounders identified and taken into account in the design and analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are you certain that the overall effect is due to the exposure/treatment/management?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is this paper related to Feasibility, Appropriateness, Meaningfulness or Effectiveness (or a combination)?	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>		
10. What level is this rated at (1-4)	<input type="checkbox"/> <input type="checkbox"/>		

Overall Appraisal Include
 Exclude
 Seek further info.
 Comments (Including reasons for exclusion)

JBI Data Extraction Form for Experimental Studies	
Reviewer	Date
Author	Year
Journal	Record Number

Study Method

- ☐ RCT
☐ Quasi-RCT
☐ Other

1. Participants

- 1.1 Setting (e.g geographical and care setting)
- 1.2 Population under study
- 1.3 Sample size (Nos in each intervention/arm)
- 1.4 Characteristics of the groups

2. Interventions (list all)

Intervention 1

Intervention 2

Intervention 3

2.1 Follow up period (*length of time from beginning participation to end of follow up*)

3. Clinical outcome measures

Outcome Description	Scale/measure

4. Study results

a) Dichotomous data

Outcome	Intervention () number / total number	Intervention () number / total number

Comment on Outcome measures

b). Continuous data

Outcome	Intervention () mean & SD (number)	Intervention () mean & SD (number)

5 Overall Assessment of the study

5.1 How well does this study minimise bias and in what direction (put in ++, +, or -)?

5.2 Can you comment on the methodological rigour and the statistical power and indicate the degree to which you consider the results are due to the intervention?

6. Funding

Who funded the study?

7. How does this study help to answer the following questions?

- a. What present knowledge and practices are identified as underpinning bereavement care?
- b. In what ways are individuals and organisations involved in bereavement care?
- c. What is the experience of bereavement care?
- d. What interventions are effective in bereavement care?
- e. What are the outcomes of bereavement care?

Any additional comments that relate the outcomes to any methodological issues

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research			
Reviewer	Date		
Author	Year		
Record Number			
	Yes	No	Unclear
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Feasibility, Appropriateness, Meaningfulness rating. (1-4)			

Overall Appraisal Include
 Exclude
 Seek further info.
 Comments (Including reasons for exclusion)

Study Description

Methodology	
Method	
Intervention	
Setting	
Geographical	
Cultural	
Participants	
Data Analysis	

Author's Conclusions

Comments

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete YES

JBI QARI Critical Appraisal Checklist for Text & Opinion			
Reviewer	Date		
Author	Year		
Record Number			
	Yes	No	Unclear
1. Is the source of the opinion clearly identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the source of the opinion have standing in the field of expertise?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are the interests of patients / clients the central focus of the opinion?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the opinion's basis in logic / experience clearly argued?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the argument developed analytical?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there reference to the extant literature / evidence and any incongruence with it logically defended?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the opinion supported by peers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feasibility, Appropriateness, Meaningfulness rating. (1-4)			

Overall Appraisal Include
 Exclude
 Seek further info.
 Comments (Including reasons for exclusion)

Study Description

Type of Text	
Those Represented	
Stated Allegiance/Position	
Setting	
Geographical	
Cultural	
Logic of Argument	

Author's Conclusions

Comments

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

APPENDIX 2: JBI Levels of Evidence for use with the Bereavement Review

JBI Levels of Evidence for use with the Bereavement Review

Level of Evidence	Feasibility F(1-4)	Appropriateness A(1-4)	Meaningfulness M(1-4)	Effectiveness E(1-4)
1 High quality evidence with low risk of confounding/bias or trustworthiness	Qualitative/Descriptive research with unequivocal synthesised findings	Qualitative/Descriptive research with unequivocal synthesised findings	Qualitative/Descriptive research with unequivocal synthesised findings	Systematic Review/Meta-analysis (with homogeneity) of RCTs Or 1 or more large experimental studies with narrow confidence intervals
2 Some risk of confounding/bias or trustworthiness in presented evidence	Qualitative/Descriptive research with credible synthesised findings	Qualitative/Descriptive research with credible synthesised findings	Qualitative/Descriptive research with credible synthesised findings	Systematic Review/Meta-analysis of studies with quasi –experimental /cohort/case-control groups. Quasi-experimental studies (eg. without randomisation) Cohort studies (with control group) Case-controlled studies L1 studies with some risk of bias
3 Increased risk of confounding/bias or trustworthiness in presented evidence	Text/opinion with credible synthesised findings Qualitative/Descriptive research with unsupported findings Systematic review with mixed studies	Text/opinion with credible synthesised findings Qualitative/Descriptive research with unsupported findings Systematic review with mixed studies	Text/opinion with credible synthesised findings Qualitative/Descriptive research with unsupported findings Systematic review with mixed studies	Observational studies/Mixed methods without control groups Systematic review with mixed studies L1 or 2 studies with increased risk of bias
4 High risk of confounding/bias or trustworthiness in presented evidence	Text/opinion without explicit critical appraisal Literature Reviews without explicit methodology Qualitative/Descriptive research with high risk of confounding/bias	Text/opinion without explicit critical appraisal Literature Reviews without explicit methodology Qualitative/Descriptive research with high risk of confounding/bias	Text/opinion without explicit critical appraisal Literature Reviews without explicit methodology Qualitative/Descriptive research with high risk of confounding/bias	Expert opinion without explicit critical appraisal, or based on physiology, bench research or consensus. Literature Reviews without explicit methodology High risk of confounding/bias in any type of study

APPENDIX 3: FAME Scale

FAME Scale

Evidence of 'Feasibility'

Feasibility is the extent to which an activity is practical and practicable. Clinical feasibility is about whether or not an activity or intervention is physically, culturally or financially practical or possible within a given context.

Evidence of 'Appropriateness'

Appropriateness is the extent to which an intervention or activity fits with or is apt in a situation. Clinical appropriateness is about how an activity or intervention relates to the context in which care is given.

Evidence of 'Meaningfulness'

Meaningfulness is the extent to which an intervention or activity is positively experienced by the patient. Meaningfulness relates to the personal experience, opinions, values, thoughts, beliefs, and interpretations of patients or clients.

Evidence of 'Effectiveness'

Effectiveness is the extent to which an intervention, when used appropriately, achieves the intended effect. Clinical effectiveness is about the relationship between an intervention and clinical or health outcomes.

APPENDIX 4: Advisory Group Members

Advisory Group

Dr John Costello, Lecturer in Palliative Care Nursing, Manchester University.

Liz MacInnes, Senior Research and Development Fellow, RCN/NICE Collaborating Centre for Nursing and Supportive Care, Oxford.

Dr Colin Murray Parkes, Honorary Consultant Psychiatrist to St Christopher's Hospice, Sydenham and Consultant Psychiatrist to St Joseph's Hospice, Hackney. Formerly Senior Lecturer in Psychiatry, The Royal London Hospital Medical College and Member of Research Staff at The Tavistock Institute of Human Relations.

Eileen Wheeler, Children and Young Peoples Support Worker (Including bereavement), Cancer Support Centre, CLAN House, Aberdeen.

Dr Rick Wiechula, Director of Collaboration & Evidence Translation, The Joanna Briggs Institute, Adelaide

Stewart Wilson, Director of CRUSE Bereavement Care Scotland

APPENDIX 5: Issues Raised at meeting with NHSQIS, SEHD and NES and the Review Group

At a meeting to discuss the draft report with members of NHSQIS, SEHD and NES the overall key messages were presented. The ensuing discussion highlighted the breadth of the subject but also some of the main areas that might form future activity in policy and practice. These are presented below:

- Within the themes there are clearly issues that are related to psychological care provision in general. This includes for the bereaved: the need for appropriate assessment to identify those who are most vulnerable and at risk, provision of consistent and accurate information, tiered models of care that are linked to competency frameworks and services that are then configured accordingly.
- Any outcomes from this review need to consider and anticipate the future so that it is 'future proofed'.
- Care and support, in conjunction with high quality information and communication should be available in all contexts.
- Standards should be available so that both professionals, patients and their relatives know what to expect.
- Anticipating care needs for the bereaved 'anticipatory bereavement' would be beneficial to consider and would accord with risk management perspectives
- A community of practice or Centre for Bereavement Care, which might represent several disciplines/groups could be useful.
- Leadership and ownership of bereavement and bereavement care at a local level would enhance co-ordination and quality of care
- Education for staff is a prominent feature in the review and could be linked to competencies and tied to the Knowledge and Skills Framework.