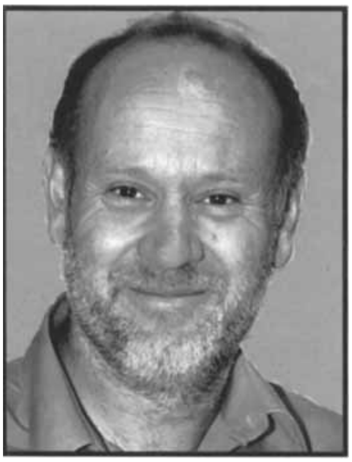
A literature review on bereavement and bereavement care

Developing evidence-based practice in Scotland



Peter Wimpenny RGN BSc CertEd PhD

Associate Director
Joanna Briggs Collaborating Centre for Multi-Professional Practice
School of Nursing and Midwifery
Robert Gordon University
Aberdeen, Scotland

Co-authors: **Rachel Unwin, Paul Dempster, Maggie Grundy, Fiona Work, Alison Brown, Sylvia Wilcock**

THERE HAS BEEN AN INCREASED INTEREST in bereavement issues within the UK healthcare system, prompted by the organ and tissue retention scandals (Kennedy, 2001) and the deaths of children undergoing cardiac surgery (Redfern, 2001). The response of health services has been to seek ways of improving care for bereaved people, particularly just before and at the time of death. With the majority of deaths now occurring in healthcare settings rather than at home (Centre for Advancement of Health, 2003), there is increasing pressure on health and social care practitioners to provide the best possible bereavement service. In some cases, such as in acute clinical care settings, there is often only one opportunity to achieve this.

Within the UK, the England, Wales and Northern Ireland health departments have sought to enhance bereavement care through bereavement co-ordinators (Department of Health, 2006; Northern Ireland Government, 2007). It is intended that these co-ordinators develop the care of bereaved people by, for example, initiating and improving education and training of staff at all levels, reviewing procedures and processes so that they are more appropriate and easier for bereaved people to navigate, and ensuring relevant facilities are available. This is no mean task in organisations that are focused on those suffering ill health rather than bereavement. However, there is evidence that an increasing number of complaints received by health services are related to poor death and bereavement experiences, eg 54% in England (Healthcare Commission, 2007), so health services, as well as health and social care practitioners, are keen to address this and improve practice.

ABSTRACT

This paper reports on a systematic literature review of bereavement and bereavement care commissioned in Scotland to assist the development of policy and practice there. The review identified and appraised papers from a range of health and social care settings in which bereavement care is a feature, such as acute, hospice- and hospital-based care including neonatal and obstetric, community and primary care, mental health and learning disability services, and care of older people, families and children. Specific types of death were also reviewed, eg traumatic and from diseases such as HIV/AIDS. Key messages for each setting and type were identified and overall themes were drawn out which cut across all settings and types. These, it is proposed, represent important features of bereavement and bereavement care which, if acknowledged and addressed, could enhance services.

In Scotland the Scottish Executive Health Department, in conjunction with NHS Quality Improvement Scotland and NHS Education for Scotland, set out in 2005 to consider how bereavement and bereavement care should be developed in policy and practice terms. The first phase of this process was their provision of funding and support for a systematic literature review and it is the results of this review (Wimpenny *et al*, 2006) that are presented here.

Setting up the review

There is no doubt that the available literature and material relating to this topic is immense: a recent internet search produced over one million hits for the term 'bereavement'. Our search focused on professional, published literature but it also included literature and other material that was unpublished, particularly reports or information for the bereaved.

EDITOR'S NOTE

Although focused on the situation in Scotland, the lessons learned by Peter Wimpenny and his team have much wider relevance. This article gives a concise and accessible account of the conclusions that can be drawn from the current literature on family care in the face of death and bereavement. It deserves our close attention and should have a major influence on the planning of palliative care and bereavement services. CMP

The objectives for the review were to:

- 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

We had five questions that we sought to answer with the review:

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?

With hindsight these aims were ambitious but they did provide a direction for the review, albeit one which was rather all-encompassing. We used a small number of search terms in an attempt to capture the breadth of literature before beginning to funnel this down (* is a truncation of a word to capture variations in spelling).

- 'Bereavement care'
- '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.

We identified an initial 6,252 papers covering a period from 1990 to November 2005. The final number of papers considered was 407, and in addition we included a range of seminal or classic pieces of work, such as those by Parkes (1996), Vachon (1980) and Stroebe *et al* (2001).

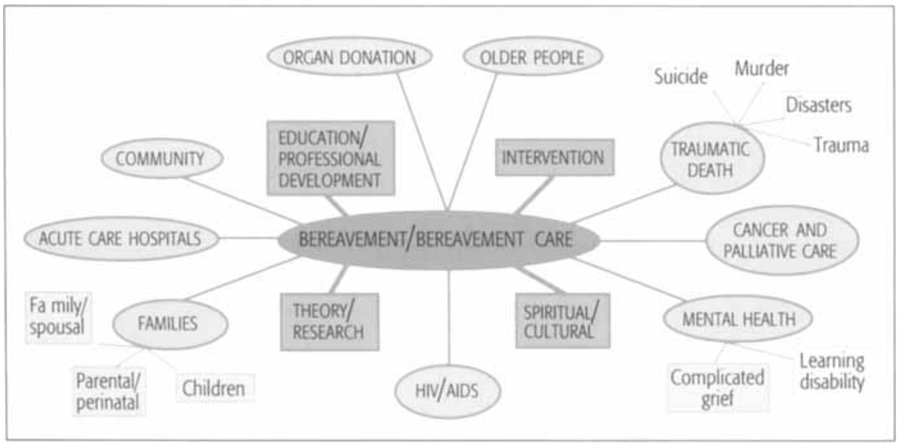
As we began to appraise the range of material it became evident that the questions were only useful as a broad frame of reference and the organisation of the literature would have to be in a different form. Specific areas of bereavement and bereavement care were therefore identified (see map below) and formed the basis for the written report. These areas provided a means by which we could isolate key parts of health, social care, bereavement and bereavement care in general and identify the key messages. We then analysed the key messages in each area for common themes and built an overall view of bereavement and bereavement care. The following 13 overall messages are ones which were consistently reported across the majority of areas and which we identified as important in developing policy and practice in Scotland.

OVERALL MESSAGES

1. Grief is a normal process.

Whilst there will be common areas of disruption in physical, psychological and social functioning after a death, it is estimated that the majority (90-95%) of bereaved people will grieve 'normally' with a range of support, usually family, friends and other social networks. However, the range of need is difficult to quantify as the way people grieve can vary and therefore the informational and emotional support needs are also varied, as should be the available services (ie information, advice and support). The manner in which people grieve, whilst having some universal components, is also governed by cultural expectations, rituals and norms.

Map Key areas identified from the literature review



The medicalisation of bereavement has been raised by many writers, as bereavement can be viewed as a 'condition' in need of diagnosis and treatment. There is little to suggest that such an approach is helpful, although understanding the bereavement process so that appropriate and timely interventions for those in need of support can be implemented is important.

Interventions for those who are grieving normally have, at present, been shown not to be helpful, and for some may actually diminish their natural, healthy responses and support networks.

2. A compassionate approach to all procedures and processes surrounding death can impact positively on bereavement. The involvement of relatives and families is essential.

A compassionate approach by *all* professional and non-professional staff is consistently reported by bereaved people as having a positive effect. Conversely, approaches which do not relay such compassion can impact negatively. It is often the case, in many situations, that bereavement support is targeted at a particular individual and emotions of other family members may be ignored. It may be beneficial to consider how to involve them, either to offer them support also or to help them support the family.

3. Risk factors for abnormal responses are amenable to assessment.

The response to bereavement is governed by a range of factors such as sex, age, relationship to deceased, context of the death, previous mental health and levels of social support. These factors could be used to assess for risk of prolonged or intense grief. It may be possible to construct simple but effective assessment tools for use by professional and non-professional groups in all settings and there is evidence that some already exist. The linkage between voluntary and statutory services appears crucial in providing the structure and process for risk assessment so that there is seamless provision. For example, the befriending service so vital to many with limited social support should be able to assess for risk and refer onwards, whilst still remaining involved in the support process.

It has been suggested that it is possible to establish a 'diagnosis' of complicated or traumatic grief at about six months after the death (some would suggest this can be identified earlier). Complicated/traumatic grief may be accompanied by depression and anxiety and requires appropriate treatment.

4. Interventions should be tailored to need. Specific groups of bereaved people may require different forms of intervention.

It is important to offer a range of interventions as the needs of different groups, eg men, women, children, adolescents, require different approaches. Many interventions, from self-help groups through to different forms of psychotherapy and pharmacology, have been shown to have some effect for those with associated depression and anxiety. Those identified as at higher risk of bereavement problems appear to benefit most from any interventions. However, to achieve maximum benefit it appears essential that the voluntary and statutory sectors work together to ensure appropriate provision of a wide range of services and to allow bereaved people to move readily between the different sectors.

5. Follow-up has been identified as important, particularly by bereaved people.

There is no set way to provide follow-up after the death of a patient or client. At present follow-up support and information is often limited to tasks which must take place after a death – a focus picked up in the unpublished literature. The quality and type of follow-up also seems to depend on individuals championing bereaved people, rather than being built into organisational procedures. However, whilst relationships with staff are important around the time of the death, many bereaved families rely on their own families for support and reject professional intervention.

Seeking answers can be an important factor. Relatives are often looking for an opportunity to get more information and should not be discouraged from, for example, seeing the body or being present during attempts at resuscitation.

Follow-up also allows professionals to hear how their care was received and learn from those who experienced it. Questions can be raised, eg how well was the care managed, what could be improved, what needs to be addressed and changed. The responses can then be fed back into the system to inform practice.

5. There are a range of information needs that need to be addressed at local and national levels.

The need for information has been addressed in some areas and sadly neglected in others. Death is unique for each person and impacts on families in many different ways but, even allowing for that, there appears to be a confusing array of documents available following a death.

This review highlighted the variability in the quality of materials, perhaps reflecting the level of care and consideration each organisation puts into its packs and core documents, ranging from high-quality, glossy packs to third-generation photocopies. The extensive duplication of materials between organisations means there is also, potentially, a great deal of waste. Resources used replicating materials could be better spent in providing information about key aspects of particular deaths.

Rather than produce poor-quality, photocopied materials it may be better to offer the core booklets already available and supplement these with sheets containing local information. Using what is available would considerably cut costs and ensure that local services are promoted uniformly.

7. There are hidden socio-economic factors, particularly for some bereaved groups, that need to be considered.

Death increases the risk of social and economic disadvantage. The journey to death and, for those who are left behind, the journey beyond, has a number of additional worries or factors that are not always made explicit in the literature. When someone dies, the loss of income or benefits can have a severe impact on the household, particularly when the parent(s) or main earner dies.

Within areas affected by deprivation and disadvantage there are fewer opportunities for bereaved people to access health and other support structures. This in turn increases risk, both before and after death. The lack of access can worsen an already poor situation. If the standards of existing palliative care are extended to all settings, this should include aspects of assessing and giving financial advice. Good financial advice may reduce some of the problems associated with bereavement and the financial costs of this support could be set against the potential long-term expense of bereavement. Support in the community should not be seen as isolated, but integral to the financial implications of bereavement.

8. Cultural and spiritual factors, including issues of stigma, need to be incorporated into all areas of bereavement care.

Spiritually and culturally competent care should be an integral part of health and social care. Spirituality is not limited to one place in the report; it comes up at many points in various different areas. Hence it is difficult to talk of a spiritual or, for that matter, a cultural dimension which is distinct.

Increasing secularism has meant that we have lost some of the rituals and responses that we once had for death and dying. The rise of individualism highlights the potential isolation in lack of faith, exacerbated by the growing self-awareness of people facing their own mortality, pursuing a range of personal issues in their own search for meaning.

We need to question whether spiritually and culturally competent care is an integral part of our health care system. Do we have the necessary range of appropriate religious and spiritual personnel available to be involved in supporting not just patients and their families but also members of staff?

The stigma associated with some deaths, such as those from HIV/AIDS and suicide, should also be addressed and incorporated into care at all levels. There are some universal components of grief that need to be understood in a cultural context.

9. A co-ordinated approach to bereavement and bereavement care that cuts across statutory and voluntary agencies is required.

As the range of interventions needs to be broad, it is advantageous to have a range of services (statutory and voluntary) for provision and access. However, there is a need to establish what is available so that gaps can be identified and local need assessed. Local leadership for bereavement and bereavement care may be beneficial to ensure co-ordination and appropriateness of available services and information. Bereavement is a universal phenomenon that needs multi-agency/professional involvement to ensure coverage across health and social care, education and workplace settings.

10. Standards, policies and guidelines for bereavement care should be considered for all areas.

National standards/best practice for bereavement care, potentially based on that from palliative care, could be adopted in all health and social care settings. Guidance on specific aspects should be considered, for example a clinical guideline or best practice statement dealing with complicated/traumatic grief, including associated depression and anxiety.

There is no agreed approach to the type and form of policy and protocols for bereavement care. However, it appears appropriate to ensure that such policy and protocol exists in all settings (health and social care, education and work places).

11. Education for health and social care professionals and others is identified as in need of development.

Education for professionals and those involved in bereavement care was consistently reported as in need of development and might best be available nationally since all health and social care areas are affected. It was suggested that it should, wherever possible, be multi-professional/multi-agency in orientation, although some groups may have particular educational needs. It should also work with and acknowledge the experiences of loss of the students or participants.

Death and bereavement are areas of social/cultural life that are becoming increasingly hidden and as a result the understanding of these, and engagement with them, is limited. The inclusion of death, dying and bereavement in school curricula could increase awareness and understanding, and may impact on bereavement more generally at a societal level.

Facilitating students or participants attending courses on grief and bereavement needs considerable skill and that needs to be acknowledged and addressed. In addition teachers in all educational settings are often confronted with bereaved students and need to be prepared and supported.

12. Research into bereavement and bereavement care is particularly difficult but essential in developing services.

It is acknowledged that undertaking research into bereavement and bereavement care is challenging because these are sensitive topics and researchers encounter difficulties with recruitment and ethics. However, these challenges do not appear to be insurmountable and there is a range of expertise and experience available.

There is considerable evidence across all the areas covered that research in bereavement and bereavement care would benefit from larger, better-conducted studies, particularly to establish effectiveness of interventions. The approach and reporting of studies of all types often make it difficult to generalise findings and apply them to bereaved people in a wider context.

13. Establishing a centre for bereavement care may provide a focal point for developing research, education and practice in Scotland.

The range of disciplines and approaches that contribute to bereavement and bereavement care literature is significant and tends to result in a fragmented approach to research, education and practice. The aspects that may be valuable in developing services, highlighted in the key messages above, would benefit from a more co-ordinated approach linking professionals and voluntary groups. Creating a centre could address these problems, focus on the particular Scottish context and provide expertise and advice in the future.

Conclusion

There is a considerable volume of writing and research on bereavement and bereavement care but, after a systematic funnelling and rigorous review and appraisal process, we consider that the overall messages listed here are ones which are, to a great extent, universal. Whilst much of the evidence reviewed was considered as low level in pure research terms (SIGN 50, 2002), this does not mean it should be ignored or that there is not a need for action. There are important messages here that, if considered, developed and acted upon, could enhance bereavement care in the future.

This literature review formed the first of two phases. The second is a consultation and mapping of practice, and the setting up of a bereavement workshop, both of which will contribute to evidence-based policy and practice for bereavement care in Scotland. ●

p.wimpenny@rgu.ac.uk

References

Center for the Advancement of Health (2003). Report on bereavement and grief research. http://www.cfah.org/pdfs/griefreport.pdf

Department of Health (2006). Bereavement. http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Bereavement/fs/en

Healthcare Commission (2007). *Spotlight on Complaints*. London: Commission for Healthcare, Audit and Inspection. www.healthcarecommission.org.uk/_db/documents/spotlight_on_complaints.pdf

Kennedy I (2001). *Learning from Bristol: Report of the Public Inquiry into Children's Heart Surgery at Bristol Royal Infirmary 1995*. Norwich, Norfolk, UK: HMSO. http://www.bristol-inquiry.org.uk

Parkes CM (1996). *Bereavement: Studies of Grief in Adult Life*. London/New York: Routledge.

Redfern M (2001). *The Royal Liverpool Children's Inquiry Report*. London: The Stationery Office. httpp://www.rlcinquiry.org.uk/

SIGN (Scottish Intercollegiate Guideline Network) (2002) *Publication 50, A Guideline Developers Handbook*. Edinburgh, UK: SIGN. http://www.sign.ac.uk/guidelines/fulltext/50/index.html

Stroebe MS, Hansson RO, Stroebe W, Schut H (eds) (2001). *Handbook of Bereavement Research: Consequences, Coping and Care*. Washington DC: American Psychological Association.

Northern Ireland Government (2007). Human organs enquiry: implementing the report. http://www.dhsspsni.gov.uk/index/hss/hoi-home.htm

Vachon (1980). A controlled study of self-help interventions for widows. *American Journal of Psychiatry*; **137**: 1380-1384.

Wimpenny P, Unwin R, Dempster P *et al* (2006). Literature review on bereavement and bereavement care. www.rgu.ac.uk/files/BereavementFinal.pdf