Bereavement Assessment Practice in Hospice Settings: Challenges for Palliative Care Social Workers

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Abstract

The management and delivery of bereavement support services in palliative care settings present practical and ethical challenges. A national survey, conducted in 2007, examined bereavement practice in ten Marie Curie hospices across the UK. This qualitative study was undertaken using semi-structured telephone interviews with Bereavement Service Leaders located in each hospice. Although findings revealed that bereavement services were in operation and had been reviewed in response to the National Institute for Clinical Excellence Guidance (2004) and all bereaved families were offered support, there was no standardisation of service delivery across sites. Multidisciplinary team meetings facilitated shared decision making for bereavement follow-up and expanded and clarified documentation completed by nursing staff around the time of the patient’s death. However, there was ambiguity regarding professional ‘duty of care’ and agency
responses to bereaved individuals who were suicidal. Questions were raised around clinical effectiveness, reliability and professional accountability. The study highlighted ethical issues centred on documentation, user participation and consent, and found staff training was variable across the ten hospices. The findings have informed the development of a post-bereavement service model that has been subsequently implemented across Marie Curie Cancer Care.

Keywords: Bereavement, assessment, hospice, social work

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Introduction

The World Health Organisation (2008) has defined palliative care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness’. The goal of treatment is to alleviate distress and cater for the physical, psychosocial, medical and spiritual needs of service users (Farsides, 2009).

Palliative care extends beyond patient care to continuing support for bereaved family relatives (Payne and Relf, 1994; NICE, 2004; Department of Health, 2005; WHO, 2008) and it has been argued by key authors that bereavement services should be available to promote health or reduce the risk of distress, dysfunction or complicated grief (Walshe, 1997; Kelly et al., 1999; NICE, 2004; Agnew et al., 2008).

Whilst the difficulties associated with offering bereavement services and conducting bereavement assessments have been recognised for some time (Relf et al., 2008), they are both acknowledged to be important areas of service delivery.

Current UK policy

A number of key documents have set out the principles, standards and core elements that currently underpin and shape the delivery of bereavement services across the UK. The NICE Guidance on Cancer Services (2004) has been adopted by all Marie Curie Cancer Care (MCCC) hospices. It recommends a three-component model of bereavement, aimed at ensuring that individual needs are addressed through appropriate levels of service provision (NICE, 2004, p. 160).

The first component of the model recommends that all bereaved individuals should be offered information and encouraged to utilise existing informal support systems (Walshe, 1997; Jordan and Neimeyer, 2003; NICE, 2004). This approach aims to promote resilience and respects that not all bereaved people experience acute distress by their loss (Zhang et al.,
2006). The second component addresses individuals who, following assessment of need, may require more formal bereavement services to review and assist them with their grief experience. The third component focuses on bereaved individuals who are at risk of lasting physical and mental health consequences and who will require more specialist bereavement support. The NICE Guidance recommends that bereavement services should have robust assessment methods in place to identify those in need of services within component two and to have mechanisms in place to make onward referral to component three, where necessary. In line with the NICE model, MCCC currently offer bereavement information booklets; bereavement support through remembrance services; bereavement groups; individual support from trained staff and volunteers; and specialist support from health and social care professionals.

In addition to the NICE Guidance, the following documents were developed by the Department of Health (England and Wales), NHS (Scotland) and the Department of Health, Social Services and Public Safety (Northern Ireland) to provide advice and guidance on end-of-life and bereavement care: *When a Patient Dies: Advice on Developing Bereavement Services in the NHS* (Department of Health, 2005); *The End of Life Care Strategy* (Department of Health, 2008); *Living and Dying Well: A National Action Plan for Palliative and End-of-Life Care in Scotland* (NHS, 2008); and the *Northern Ireland Health and Social Care Services Strategy for Bereavement Care* (DHSSPS, 2009). Although these documents contain the basic principles, standards and elements considered necessary in developing bereavement services locally, they do not recommend methods for bereavement risk assessment.

Loss and grief

Grief is a natural response to human loss. Each loss is unique and the requirement for bereavement support varies according to the personal resilience and individual needs of each person affected (Machin, 2009; Agnew *et al.*, 2010). Although the majority of bereaved individuals employ their own inner and informal resources to adapt to their loss, a proportion may be at risk of developing complicated or prolonged grief, in which they experience lasting physical or mental health problems. This ‘at risk’ group may require formal and professional bereavement support (Payne and Relf, 1994; Stroebe *et al.*, 2001).

Diagnosing a period of prolonged grief as a distinct medical syndrome remains controversial. Bonanno (2006) questioned the validity of complicated grief as a separate syndrome, distinct from other mental health problems. Machin (2009, p. 46) also stated that definitions of complicated grief are elusive and absent from any official diagnostic manuals. However, recent research (Prigerson *et al.*, 2009) proposes updated diagnostic criteria for
forthcoming versions of the current *Diagnostic and Statistical Manual for Mental Disorders* (DSM-IV) and *The International Statistical Classification of Diseases and Related Health Problems* (ICD-10). This research indicates that a complicated or prolonged grief disorder diagnosis can be made if a person experiences cognitive, emotional and behavioural symptoms, separation distress and impairment of functioning on a daily basis, for more than six months after bereavement (Prigerson et al., 2009). The challenge for health and social care professionals is to identify individuals who are at risk of lasting physical or mental health problems and to offer bereavement support to reduce their risk of an adverse bereavement outcome (Prigerson et al., 2009). This paper aims to highlight challenges in practice for palliative care social workers involved in assessing bereavement risk.

### History of bereavement assessment in hospice settings

The origins and history of bereavement assessment practice have been well documented (Parkes, 1981; Payne and Relf, 1994; Relf, 2004; Reith and Payne, 2009). A number of papers report studies of adult bereavement services in hospice and palliative care settings across the UK and Ireland (Parkes, 1981; Payne and Relf, 1994; Field et al., 2004). Their findings have indicated a range of philosophies regarding bereavement assessment practice and patterns in service delivery and highlight the need for proactive screening of grief reactions. Whilst both formal and informal approaches have been developed, informal assessment methods have been criticised, as they may lead to inconsistent practice and *ad hoc* support (Payne and Relf, 1994).

Formal bereavement assessments, which commonly apply written checklists for risk factors or perceived coping strategies, have been incorporated into hospice practice since the 1970s. This trend was initiated by Dr Colin Murray-Parkes, who developed a formal checklist based upon assessment of family members by palliative care staff pre and post bereavement (Kristjanson et al., 2005). Parkes promoted its implementation on both economic and humanitarian grounds (Parkes, 1981, 1993; Parkes and Weiss, 1983). In 2004, Field et al. reported that 43 per cent of hospices in the UK formally assessed the need for individual support and 51 per cent had no formal processes for bereaved people to provide feedback about such support.

Problems with formal methods have been reported in terms of their limited reliability to predict bereavement outcome (Relf, 2004). For instance, Parkes’ Bereavement Risk Index (BRI) has since been found to have limited reliability in accurately predicting bereavement outcome (Beckwith et al., 1990; Levy et al., 1992). When subjected to Chronbach’s Alpha reliability test, the eight-item BRI developed by Parkes (1993) was found to be less reliable than the four-item version developed by Kristjanson et al. (2005).
More recently, Relf et al. (2008) highlighted further problems with formal methods, which include a lack of information due to briefer hospice admissions, limited user involvement and nursing staff having the time, skills and knowledge necessary to conduct assessments.

However, formal written assessments continue to be widely promoted to help ensure accurate collection of information, demonstrate decision making, avoid subjectivity of clinical judgements and facilitate audits of practice (Parkes, 1981; Walshe, 1997; Lev and McCorkle, 1998; BrintzenhofeSzoc et al., 1999; Walshe-Burke, 2000; Payne, 2001; Field et al., 2004; Kristjanson et al., 2005; Reid et al., 2006; Relf et al., 2008).

The assessment process

Relf (2004) states that bereavement risk assessment involves the interrelationship and cumulative impact of situational, environmental and individual factors that influence the course of grief.

For several years, the efficacy and effectiveness of bereavement interventions have been questioned in the research literature. It has been stated that providing bereavement support to individuals who are resilient may be unhelpful or possibly even harmful (Walshe, 1997; Kristjanson et al., 2005; Schut and Stroebe, 2005; Wimpenny et al., 2008). This controversial finding was first published by Neimeyer (2000). However, a recent evaluation of the empirical foundations for these findings has found that there is no statistical or empirical evidence to support claims about treatment induced deterioration effects (Larson and Hoyt, 2007).

Relf (2005) advocates that agencies should reach out to those who may be at risk of poor bereavement outcome and ensure that services are accessible to all bereaved people. She recommends that organisations should provide written information to facilitate self-referral. This approach aims to respect resilience and autonomy, to be less stigmatising and allows active engagement in bereavement services by consenting individuals (Reith and Payne, 2009).

Reith and Payne (2009) suggest that consent should be obtained prior to conducting a bereavement assessment. As part of this process, professional expectations and proposed support options should be explained and individual autonomy and choice respected.

Although hospice or palliative care teams are uniquely placed to assess need continuously during their involvement with the patient or carer (Field et al., 2007), concerns have been raised about the accuracy or reliability of information in written bereavement assessments. First, observations by hospice staff around the time of the patient’s death, when relatives are distressed, are not necessarily reliable (Reith and Payne, 2009). Second, relatives may be unaware that they are being assessed for bereavement support or that records are being maintained to which they have not
consented (Relf et al., 2008). Finally, staff may be reluctant to ask intrusive questions (Payne and Relf, 1994).

National guidance developed by Relf et al. (2008) proposes how to address some of these issues. The guidance recommends using the Range of Responses to Loss (RRL) matrix, which is a theoretical framework designed to inform the development of documentation for continuous assessment from the point of admission into early bereavement. Information may be gathered through observation and discussion with the family, both pre and post bereavement, and through discussions with the multidisciplinary team (MDT). The RRL matrix uses a narrative approach to enable people to tell their story and to identify their coping style and vulnerability to developing enduring mental or physical health problems (Relf et al., 2008). At the time of this study, the RRL matrix had not been tested for reliability and validity and was not adopted by MCCC.

Existing bereavement assessment practice across the majority of MCCC hospices involved the use of an eight-item bereavement checklist. This was a locally developed screening tool informed by existing theory. It was designed to collate information on a bereaved person’s predisposing physical, mental, emotional, financial and social vulnerability to impending or actual loss and mirrors the formal assessment process utilised by 43 per cent of UK hospices (Field et al., 2004). Across nine MCCC hospices, bereavement checklists were initiated by palliative care social workers at the point of patient admission. These checklists were completed by nursing staff around the time of the patient’s death and subsequently discussed at MDT meetings. This information was used by Bereavement Service Leaders (BSLs) to inform the timing and level of bereavement follow-up support offered. In line with NICE Guidance (2004), MCCC staff were required to provide written information and offer bereavement support to all bereaved individuals within twelve weeks of the patient’s death.

Across MCCC hospices, there was disparity in the terminology used to describe bereavement assessment documentation (e.g. ‘checklist’, ‘referral form’, ‘risk assessment tool’ or ‘bereavement vulnerability assessment’). In the interests of clarity, it will hereafter be referred to as the ‘bereavement checklist’ or ‘checklist’.

The role of palliative care social work

Social work is an integral component of the MDT service model within palliative care. It may be argued that compared to clinical interventions, social work involvement is less well understood and valued. This is evidenced by some authors who question the justification for psychological and social interventions as part of specialist palliative and end-of-life care (Randall and Downie, 1999, 2006). However, such criticism fails to recognise that
patients’ family lives may be chaotic (Reith and Payne, 2009), due to impending or actual bereavement. Unlike many fields of social work, specialist palliative care social workers are exclusively involved with two groups of service users: those diagnosed with a life-limiting illness and those who are experiencing bereavement (APCSW, 2006, p. 6).

In MCCC, in addition to the checklist, a psycho-social assessment is normally conducted by social workers as an integral part of the holistic care of patients and families.

Research setting

MCCC is the largest non-statutory provider of palliative and end-of-life care in the UK. In 2005, the agency revised its bereavement service and developed bereavement standards in response to NICE Guidance (2004). The standards provided a rationale for service delivery, identified time-scales for assessment and intervention and informed training and service evaluation. However, the standards failed to clarify the professional ‘duty of care’ to bereaved individuals or recommend assessment methodology or documentation relevant to practice.

Additionally, there was no recognised, accredited or quality-assured training programme available to bereavement or nursing staff. The delivery of training was therefore inconsistent regarding content, standard and frequency. Bereavement assessment was typically based on inherited systems and existing expertise of staff and volunteers.

In February 2007, in order to review the implementation of the standards and to determine the most effective approach to bereavement assessment practice, MCCC commissioned a study to examine existing practice in its ten hospices across the UK. The study investigated the views of those responsible for the management of bereavement services in each hospice.

Method

Qualitative interviews were conducted by telephone to examine current practice within each of the MCCC hospices. Purposive sampling was used to recruit BSLs, who were nominated in line with NICE Guidance (2004). BSLs were contacted by letter and invited to participate. All those approached provided written consent to be interviewed. As this study was classed by MCCC as service evaluation, formal research ethical approval was not required. Interviews were semi-structured and were audio recorded with the consent of participants. The interview schedule was developed by the project team, based on the project aims and findings from published literature. A pilot study was conducted with one BSL in an independent hospice, which allowed for testing, feedback and amendments.
Data were collected on participants’ demographic details and current practice in relation to bereavement assessment. Views were also sought on service user involvement, availability of staff training and recommendations for service improvement.

Analysis

All audio recordings of interviews were transcribed verbatim by the principal researcher. To ensure accuracy of information, all transcripts were verified by BSLs. The principal researcher reviewed the manuscripts, identified the salient information and categorised emerging themes using thematic analysis (Ritchie and Lewis, 2005). Due to sample size, a manual method was used to devise a framework for initial coding. Transcripts were subsequently re-read, additional themes identified, points re-categorised and quotes were selected that encapsulated the semantics of emerging themes. A sample (30 per cent) of interview transcripts was read by another member of the project team and differences in interpretation were discussed and resolved by consensus.

Results

Ten respondents took part in the study and demographic details are reported in Table 1. Four key themes emerged from the data: (i) the assessment process; (ii) timing and level of bereavement follow-up; (iii) ethical issues; and (iv) staff training.

Theme One: Assessment process

All BSLs reported that upon admission, all patients underwent a holistic assessment by the MDT. The majority of BSLs ($n = 9$) indicated that the written bereavement checklist was completed, mainly by nursing staff, around the time of the patient’s death. Typically, one BSL described this process:

We start to think about issues … pre-bereavement … at any point of contact if we are getting to know patients and relatives. It is after the death that nurses fill in the documentation (P5).

BSLs indicated that their written checklist acted as an ‘aide memoir’ to assist in collating and documenting relevant information. In most cases ($n = 9$) the content of the checklist was discussed at the MDT meeting following the patient’s death, which allowed for accumulation, clarification or expansion of information. Some staffing structures promoted single worker
continuity, whereas others allocated pre- and post-bereavement work proportionate to local resources or to individual roles and responsibilities.

The majority of BSLs indicated that their checklist was based on the theoretical models of Parkes (1993) (n = 6), Stroebe and Schut (1999) (n = 1), Klass et al. (1996) (n = 1) or a narrative approach (n = 1). One BSL indicated that their hospice did not use the written checklist and instead relied on a post-bereavement assessment conducted by telephone. Those respondents (n = 7) who had inherited their assessment methodology from previous workers expressed dissatisfaction, whereas those who had revised theirs to reflect evidence-based practice were more satisfied (n = 3):

We have all moved on in our understanding about grief and realise it is more complex...we have to be more open to the whole person...how open the person is to acknowledge their grieving...the distress caused through bereavement: financial, emotional and spiritual distress. It [the assessment] looks at coping strategies...plans they have for the future, how they tackle problems, being on their own...taking on new tasks...family support or conflict, looking at the whole picture...looking at Stroebe and Schut's Dual Process Model and Continuing Bonds (P6).

BSLs believed that their bereavement checklist was enhanced by a MDT discussion (n = 6); that it helped to identify those in greatest need

Table 1 Survey sample characteristics

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that it acted as an aide memoir \((n = 3)\); that it raised the profile of bereavement work \((n = 3)\); and that it promoted service user involvement \((n = 1)\):

Each week, patients who have died are discussed. Everyone in the MDT is present. There is a discussion around peoples’ views of how that significant other has been either pre-bereavement or at the time of death and there is a decision made by the team as to whether that person needed to be contacted urgently or routinely by the bereavement support team (P6).

In relation to weaknesses in the checklist, BSLs indicated that documentation was often incomplete \((n = 4)\), and that it contained inaccurate or ambiguous information \((n = 4)\). Furthermore, there were questions raised about staff having the time and skills to gather information \((n = 2)\):

\[\text{It is only as good as the person who is doing the assessment. If you don’t have the necessary communication skills or you are naïve or hesitant to ask some of the questions, you can’t get the response you need and it comes back to training (P8).}\]

Some BSLs \((n = 3)\) reported that user involvement was poor and that assessments were only valid at the time of completion due to the possibility that individual and family circumstances may change between pre and post bereavement.

All BSLs expressed a desire for more evidence-based practice and increased user involvement in the assessment and care planning process. These sentiments are illustrated in the following quote from one BSL:

\[\text{What risk are we assessing here? If you read some research, it indicates that you cannot predict pre-bereavement how somebody is going to react. We are kidding ourselves that by ticking a few boxes, we are assessing need (P5).}\]

Despite concerns regarding the reliability of the checklist to predict bereavement outcome, it was used by the majority of BSLs to help determine the timing and nature of bereavement follow-up.

**Theme Two: Timing and level of bereavement follow-up**

All respondents expressed the view that most bereaved people do not require follow-up, but that offering information on bereavement support services increases resilience and promotes autonomy.

In accordance with NICE Guidance (2004), all respondents indicated that written bereavement information was provided within forty-eight hours of the patient’s death to minimise the risk of individuals or families ‘falling through the net’:

\[\text{When somebody dies, the nurses will meet the family and explain, amongst other things, about the bereavement support we offer... There is a booklet and in the back, there are leaflets about one-to-one support, group support}\]
and children’s support… they explain that people can contact us, and that they don’t have to wait for a letter (P2).

In keeping with NICE Guidance (2004), all BSLs indicated that their hospice offered bereavement support to individuals and families through a range of methods. These are illustrated in Figure 1. Services were accessed through self-referral or through bereavement follow-up contact. One BSL believed that repeated opportunities for service uptake were important, since ‘current pre-bereavement assessment methods were not fool proof’ (P3).

The majority of BSLs (n = 9) indicated that they would decide whether bereavement follow-up should be ‘urgent’ (i.e. within five to ten days of the patient’s death) or ‘routine’ (i.e. within twelve weeks), based on the bereavement checklist and on discussions within the MDT. However, as no validated scoring system was used to prioritise or calculate risk factors, concerns were expressed about the ability to accurately predict bereavement outcome and to determine the appropriate timing or level of response.

As previously stated, one respondent favoured bereavement follow-up and assessment by telephone contact, in order to gather accurate information ‘in negotiation and agreement with’ the bereaved individual, who could identify their own needs and decide whether they wished to engage in bereavement support:

Doing a formal risk assessment isn’t going to make any difference to whether we offer them a service or not. It is very much if the relative sees the need (P2).

Although the majority of BSLs appeared comfortable with their professional responsibilities, some indicated that agency accountability was
vague and none used a validated tool to measure complicated grief six months after bereavement:

I think there needs to be some clarity within Marie Curie to clarify the nature of support that they are willing to provide… to think about when our commitment and involvement ends and when bereavement becomes a wider community or primary care issue rather than just a Marie Curie issue (P10).

During the semi-structured interview, BSLs were presented with a scenario based on a bereaved individual disclosing a history of psychiatric illness and expressing suicidal ideation. Some respondents ($n = 6$) indicated that they would respond urgently and initiate contact with the individual’s general practitioner (GP) based on their professional ‘duty of care’, whereas others ($n = 4$) presumed that in the absence of GP contact details or consent of the individual, their ‘duty of care’ was relinquished. This raised both practical and ethical issues around consent and agency responsibilities regarding the management of suicidal individuals.

**Theme Three: Ethical issues**

Only half of BSLs ($n = 5$) indicated that family members or carers were ‘always’ informed of the bereavement assessment process and asked to consent. The remainder stated they ‘sometimes’ ($n = 2$) or ‘never’ ($n = 3$) sought consent. These ethical dilemmas are illustrated below:

> There are wider issues about all the information we collect on people and gaining consent to record it… at the minute we don’t do that and I have issues with it… records are kept on people and I don’t think they are aware of that. It needs to be clear what is documented and what purpose we do that for (P5).

Respondents expressed the view that employing bereavement assessment methods, which actively involve the service user, would ensure that subjects are aware of the nature of information recorded:

> We should not be filling out forms alone… I don’t know that service users know the form is being completed. We should be upfront… it promotes partnership and ownership. What is so secret about our assessment? We are struggling with it because we are not involving the person (P10).

There was general consensus that individuals were not being explicitly informed about the storage and use of their personal information. Although some BSLs accepted that individuals accessing professional support would expect records of contact to be kept, others believed this fact should be made explicit to the service user or that written consent should be obtained. In respect of storage of information obtained pre bereavement, practice varied across MCCC hospices. Some respondents recorded information in patient notes or on a bereavement checklist stored in the patient’s file.
a minority of hospices, separate ‘carer’ files had been introduced following implementation of data protection legislation. All BSLs reported that after the patient’s death, a ‘confidential’ file was created for each individual who requested bereavement support. In the majority of hospices (n = 7), nursing staff on duty at the time of the patient’s death requested service user consent regarding bereavement follow-up prior to forwarding the checklist to the BSL at the MDT meeting:

As part of the conversation after death, [the service users] are told how the referral to the bereavement service works and they are told how their details will be passed on (P2).

It was reported that all MCCC hospices created mechanisms to record when bereaved individuals or families requested no further contact.

**Theme Four: Staff training**

All BSLs acknowledged the benefits of receiving appropriate training to meet continuous professional development (CPD). However, there were no agency guidelines regarding minimum training requirements, qualifications or experience required by staff or volunteers who were delivering bereavement support.

A minority of BSLs (n = 3) expected bereavement staff to have relevant experience and qualifications on appointment and did not prioritise access to ongoing training. Some BSLs facilitated staff to access external training opportunities for CPD through local hospice networks, voluntary agencies and universities. Others used ‘in-house’ opportunities, where training on spirituality, loss, bereavement and grief was delivered by the education department (n = 6). All BSLs offered informal training to provide updates on bereavement counselling skills, theories of grief and loss, use of documentation and methods of assessment. A minority of respondents indicated that specialist external training opportunities were limited:

Training available to us is very limited because we are viewed as experts. I can’t think of any other organisation where they have more knowledge and experience than us. In terms of keeping ourselves up to date, we read articles…and network with other hospice social workers…to share knowledge (P6).

The study found inconsistencies in relation to the delivery of training to MDT staff by BSLs. A minority of BSLs indicated that bereavement awareness training was provided consistently (n = 2), whereas the remainder indicated that training was not prioritised due to workloads (n = 4) or was only addressed through induction programmes (n = 4). Where training was provided consistently, it was organised by BSLs, MCCC education departments or a combination of both.

Nine MCCC hospices used volunteers to assist staff with bereavement service delivery. In most cases (n = 7), the volunteers had received
between thirty and sixty hours’ structured training over a six to eight-week period prior to engagement with bereaved individuals. In two cases, volunteers were limited to receiving informal training during group supervision sessions. Some BSLs believed that volunteers’ professional qualifications obviated the need to attend structured training. In all hospices (n = 10), monthly or bi-monthly supervision was offered to bereavement volunteers and staff, which incorporated training updates.

Discussion

As illustrated by Relf et al. (2008), the difficulties associated with offering bereavement services and conducting bereavement assessments have been recognised for some time. Our results confirmed that existing provision of bereavement support across all ten MCCC hospices was in keeping with the NICE Guidance (2004). However, MCCC agency standards lacked clarity on assessment methodology, documentation and professional ‘duty of care’ towards bereaved individuals. Additionally, there was no recognised, accredited or quality-assured training programme available to bereavement or MDT staff. Whilst BSLs shared the views of others (Walshe, 1997; Aranda and Milne, 2000; Barry et al., 2002; Melliar-Smith, 2002; Relf et al., 2008) in recognising the unique opportunity within palliative care for continuous assessment, the majority were dissatisfied with their current methods. They expressed a preference for an assessment method, underpinned by modern theory, which would demonstrate evidence-based practice and promote user involvement.

There was an acknowledgement among BSLs that the majority of bereaved individuals do not require follow-up. However, they recognised that the challenge is to identify those who may be at risk of lasting physical and mental health problems and who may be unwilling or unable to access bereavement services (Prigerson et al., 2009). In relation to this group, they highlighted a lack of clarity and consistency in practice regarding follow-up procedures, staff responsibilities and onward referral systems in line with the NICE Guidance (2004).

Our results confirmed that the reliance on nursing staff to complete bereavement checklists around the time of the patient’s death was similar to findings from other studies (Payne and Relf, 1994; Field et al., 2004; Reid et al., 2006). Despite reports of the limited reliability of checklists to predict bereavement outcome (Relf, 2004), BSLs used the checklist to assess predisposing bereavement risk factors, inform the timing of follow-up contact (i.e. urgent or routine) and as an aide memoir for BSLs when individuals requested bereavement support.

Proactively offering information on services was endorsed by BSLs, who believed it would help minimise the ‘risk of people falling through the net’ and promote equity and autonomy by offering a choice of bereavement
services. In keeping with the NICE Guidance and MCCC standards, all bereaved individuals were contacted within twelve weeks of the patient’s death and offered information on bereavement services. Findings confirmed that services could be accessed freely by the individual or in response to telephone or written contact initiated by the social worker or BSL. This approach, which enables self-referral and promotes resilience, is supported by others (Relf, 2005; Relf et al., 2008; Reith and Payne, 2009).

In response to themes extracted from this research study and the reviewed literature, and in addition to the use of the existing bereavement checklist, the BSLs embarked on a project to design a post-bereavement service model (Figure 2). This new service model was drafted at a BSL workshop and was endorsed by relevant hospice staff following a period of consultation. The model includes a ‘confidential working agreement’, which is completed by bereavement staff and service users. It requires
bereavement staff to use structured documentation to assess need and plan interventions. Completion of the working agreement promotes clarity regarding consent, service delivery, ‘duty of care’, assessment methods, care planning, confidentiality and complaints procedures. The model also provides staff with a validated post-bereavement assessment tool, the Adult Attitude to Grief Scale (Machin, 2001), which has the flexibility to be used as a self-assessment or professional assessment tool for individuals engaging in post-bereavement services. When repeated, it also identifies complicated grief and measures change in the individual’s grief experience. In addition, MCCC introduced mechanisms to evaluate service user experiences of service delivery.

The study highlighted that training for nursing staff in the completion of the bereavement checklist was not always provided and required improvement. Co-ordinated training between bereavement support teams and education departments was one method to address such concerns. National standards (London Bereavement Network, 2001; Department of Health, 2005) stipulate that all staff involved in the management and delivery of bereavement services should be competent and confident to undertake their role. All BSLs recognised that despite their ‘expertise’ in specialist palliative care, all bereavement staff and volunteers need to maintain their own CPD through access to accredited or quality-assured training opportunities and should attend supervision. In keeping with guidelines for CPD study leave, BSLs agreed that all staff should receive five days’ training per annum. To enable BSLs to be accountable for the practice of bereavement staff and volunteers, they requested staff attend formal supervision at least six times per annum.

Relf et al. (2008) highlighted practical and ethical challenges for bereavement assessment practice and service delivery. Palliative care social workers have a key role in the assessment of bereavement risk in hospice settings across the UK and this research study makes a contribution to our understanding of the challenges they face.

Limitations

Although data collection was limited to BSLs representing ten MCCC hospices, findings compared favourably to three similar studies undertaken across the UK (Payne and Relf, 1994; Field et al., 2004; Reid et al., 2006). However, it should be noted that two of the studies were much larger than the study reported in this paper. One had 187 respondents, of whom 17 per cent were social-work-qualified (Payne and Relf, 1994), and the other had 248 respondents, of whom 15 per cent were social-work-qualified (Field et al., 2004). In our study, although the sample was small (n = 10), 80 per cent of participants were social-work-qualified. One representative from each MCCC hospice across the UK was purposively recruited based
on their roles and responsibilities regarding the bereavement service. Most were female (90 per cent), most were aged from forty to forty-nine (90 per cent) and all were white. Whilst this is in keeping with the main staff population of the charity, this gender, age and ethnic bias may be regarded as an underpinning weakness of the sample. It may have been beneficial to have involved other colleagues, such as nurses who completed bereavement checklists or those who delivered bereavement support. However, attempts were made to compensate for this limitation through consultation with hospice multidisciplinary teams and bereavement volunteers during the development and implementation of the new bereavement service model.

Conclusion

Participation in this qualitative study offered a forum for BSLs to reflect critically on bereavement service delivery and bereavement assessment. Questions around key areas of practice were highlighted and addressed. These included clinical effectiveness, reliability, professional accountability and ethical issues concerning user involvement, consent and data protection. In conjunction with this qualitative work, a concurrent review of bereavement assessment literature (Agnew et al., 2010) and a BSL workshop were also used as a basis to develop the MCCC bereavement service model, which has since been implemented nationally across the charity. An annual audit incorporates feedback on use of the confidential working agreement and the AAG scale, monitors the management of individuals identified to be ‘at risk’ of suicide or complicated grief and checks attendance at training and supervision. The service model and policy will continue to be audited and reviewed annually. Any revisions will be informed by policy developments and the publication of new findings from empirical research. The RRL matrix is currently being piloted in a number of UK hospices as part of an action research study and will be revisited by MCCC as part of their service model review in 2011.

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