Methodological and ethical aspects of evaluation research in bereavement
A reflection

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Abstract: Bereavement services, in common with all health, social care and counselling programmes and interventions, are increasingly required to demonstrate their clinical and cost effectiveness. This paper describes the main ethical and practical issues raised for one service (a hospice-based bereavement support service), and how they were overcome. It offers advice to other organisations and researchers on important aspects of the process, including the need to ensure good relationships with staff and professional supervision and support for the researcher. It also challenges the common view that participation in research may be harmful for bereaved people. Participants in this survey welcomed the chance to talk about their feelings, and to make a contribution to furthering understanding of the bereavement experience.

Keywords: Evaluation, methodology, measures, outcomes, hospice

There is growing recognition of the importance of providing bereavement support services (Parkes, 1995; Bereavement Care Standards, 2001; NACPC, 2001; NICE, 2004). Bereavement services in palliative care can vary considerably, from 'low level' provision, such as phone calls, hospice memorial rituals and the distribution of educational and information materials (for example, on coping), to 'higher level' types of support, such as one-to-one counselling, therapeutic groups, social activities and mutual help groups (Field *et al*, 2004). The NICE (2004) palliative care guidelines recommend three components of service provision: information about loss and grief, additional support to deal with the emotional and psychological impact of the loss and, in a small number of cases, formal mental health service intervention.

Little is known about the effectiveness of bereavement support programmes (Marquis, 1996; Payne, 2002), despite the wealth of research conducted on other aspects of bereavement, such as the identification of pathological grief reactions, the consequences of bereavement and the course of recovery (see, for example, Stroebe *et al*, 2001; Genevro, 2003; Wimpenny, 2007).

Current interventions for psychological problems are increasingly subjected to rigorous assessment in order to establish their efficacy, and empirically supported treatments are becoming a standard requirement (Chambless & Holton, 1998). Similarly, bereavement intervention programmes ought to be empirically assessed for their effectiveness and associated costs, and to ascertain the extent to which they meet the needs of bereaved people (Schut & Stroebe, 2005). Indeed, key commentators in the field consider it unethical to introduce services for the bereaved that are not well founded on robust research evidence and evaluated (Parkes, 1995).

However, a number of commonly reported methodological problems have, traditionally, characterised

this kind of research. Typically, these include choice of evaluation tools; research design; ethical concerns about using control groups; lack of random assignment to intervention and control groups; low initial participation rates, and generally high levels of attrition (Schut *et al*, 2001; Jordan & Neimeyer, 2003).

Hospice bereavement service study

This paper is based on the authors' experience of evaluating a hospice-based bereavement support service in Ireland (for a more detailed description of the study and its findings, see Roberts & McGilloway, 2008, 2010).

Very few bereavement intervention studies have been hospice-based, or have evaluated a hospice-based bereavement support service in its entirety, despite the increasingly important presence of bereavement care in palliative care settings. The research described here set out to fill this gap by conducting a comprehensive two-stage, mixed methods evaluation of all elements of a hospice-based adult bereavement support service in Dublin. These services included a monthly memorial service of remembrance; an information evening; a one-to-one support service provided by volunteers; an annual service of remembrance, and a Christmas tree lighting event.

The first phase of the study sought to assess attenders' and non-attenders' satisfaction with the services they had received. A postal survey was sent to all bereaved clients who had been invited to attend one or more of the bereavement support services provided by the hospice (n = 517). A total of 243 people (47%) returned completed questionnaires. Participants were asked to rate how satisfied they were on a five-point Likert scale. Most respondents reported that they were 'satisfied' or 'very satisfied' with the services (monthly remembrance service 86%; the information evening 85%, and the one-to-one support 70%). A number of aspects of the service that could be improved were also highlighted (eg. timing of events).

Interestingly, several statistically significant differences (p < 0.05) emerged between service attenders and non-attenders with respect to the intensity of their grief reaction (grief intensity was measured using the Texas Revised Inventory of Grief (TRIG) (Faschingbauer, Zistook & Devaul, 1987)) and other key factors (eg. relationship to the deceased). For example, those who chose to attend the bereavement information night were more distressed, as shown by their higher scores on the TRIG measure.

This phase also included a postal survey of staff and volunteers (n = 295) to ascertain their awareness and views of the services provided, and a series of one-to-one interviews with service attenders and non-attenders (n = 22) and with service providers (n = 23).

Phase two of the study mainly comprised a prospective follow-up study to assess the impact of the one-to-one Volunteer Bereavement Support Service (VBSS). An intervention group of clients (n = 69) was assessed before using the service and again, six months later. A matched comparison group of non-users (n = 36) was also assessed at both time points. The matching process is discussed further below. A broad range of outcome measures and a semi-structured interview were administered to the two groups at both time points (see Table 1).

This phase also included four one-to-one interviews and three focus groups (n = 14) with staff and volunteers involved in providing the VBSS.

Overall, the findings of phase two supported the effectiveness of the VBSS. Some significant between-group and within-group differences emerged on several key outcomes, including grief reaction, complicated grief and psychological distress (another paper covering these findings is currently in preparation). The findings provide important lessons for the implementation and development of hospice-based bereavement support services in Ireland and elsewhere.

Based on the authors' experience of conducting this study, this paper discusses some of the potentially problematic aspects of undertaking this kind of research, as highlighted in the literature. It goes on to explain issues that arose in the course of this study that other researchers might usefully consider when conducting an evaluation of bereavement services.

Comparative research designs

The inclusion of a control group is considered a key element of 'gold standard' research designs and, unsurprisingly, a number of key commentators in the bereavement field recommend this when evaluating bereavement interventions (Stroebe *et al*, 2001; Jordan & Neimeyer, 2003). However, this is often not possible, for ethical reasons. For example, in this evaluation the hospice one-to-one listening service had been offered for a number of years and it was considered unethical to refuse access to people who needed the service in order to provide a control group.

Similarly, it was not possible to recruit a waiting list control group because the waiting period for the service rarely exceeded a month. Balk (1995) suggests this is a recurring dilemma for many researchers as they strive to balance the need to conduct a valid and robust study with the imperative to protect participants from potential harm and minimise risks.

Balk further argues that the insistence on a control group may lead to less convincing results, because being denied a service may prove intolerable for many of the bereaved control group members (Balk, 1995). We adopted a compromise by recruiting a matched comparison group. However, the recruitment of such groups also presents considerable challenges, which may explain why they are similarly so often absent from evaluations in this field.

Table 1: Measures used in the evaluation study

Measure	Description
Brief COPE Inventory (Carver, 1997)	A brief 28-item measure of coping strategies or styles, including self distraction; active coping; positive re-framing; acceptance; planning; self-blame; religion; denial; humour; substance use; behavioural disengagement; venting, and seeking social support for emotional and instrumental reasons.
Brief Symptom Inventory 18 (BSI-18) (Derogatis, 2001)	An 18-item self-report symptom inventory to screen for psychological distress and psychiatric disorders.
The CAGE Questionnaire (Ewing, 1984)	A four-item interviewer-administered assessment tool to screen for alcohol abuse and other covert drinking problems.
General Help-Seeking Questionnaire (GHSQ) (Deane, Wilson & Ciarrochi, 2001)	A measure to assess future help-seeking intentions.
General Self-Efficacy Scale (GSE) (Jerusalem & Schwarzer, 1992)	A 10-item instrument that provides a measure of perceived self-efficacy, defined as optimistic beliefs about one's own ability to cope with a variety of stressors, including bereavement.
Hogan Grief Reaction Checklist (HGRC) (Hogan, Greenfield & Schmidt, 2001)	A 61-item self-report instrument designed to measure the multi-dimensional nature of the bereavement process.
Inventory of Complicated Grief (ICG) (Prigerson *et al*, 1995)	A 19-item self-report measure designed to measure the symptoms of complicated grief.
The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet *et al*, 1988)	A 12-item self-report measure of perceived social support relating specifically to support received from family, friends and significant others.
The SF-12 Health Survey (Ware, Kosinski & Keller, 1996)	A 12-item instrument designed to measure eight concepts commonly used in health status surveys: physical functioning; role limitations due to physical health problems; bodily pain; general health; vitality; social functioning; role limitations due to emotional problems, and mental health.
Semi-structured interviews	These were designed specifically for the purposes of this study and were based largely on a review of the literature. The schedules included items on biographical information; health; the context of the death, and service satisfaction.

The intervention group comprised people who had used the one-to-one listening service at the hospice over a 12-month period. We searched the hospice database of family members of patients who had died in the care of the hospice to match each of the intervention participants with a participant in the comparison group on four variables: age of deceased, gender of the participant, relationship to the deceased and time since death. These variables were chosen first because they have been identified in the literature as moderator variables that are influential in determining the effectiveness of an intervention (Jordan & Neimeyer, 2003), and second because only a limited amount of information was readily available to us about the families of patients in the hospice.

The matching process proved to be more laborious and time-consuming than anticipated so it was possible to identify and recruit only 36 matched comparison participants within the time frame of the study. The

intervention group participants who could not be matched were included in a subsequent analysis on the nature and use of the VBSS service.

In a randomised controlled trial (RCT) design both groups would be expected to be broadly similar at baseline. In addition, it would normally be hypothesised that there would be large enough differences between the intervention and control groups at follow-up to suggest a statistically significant positive (or less negative) change in the former when compared with the latter.

However, in our evaluation the intervention group members had significantly higher levels of psychological distress and grief symptoms than the matched group at baseline. The intervention group scored significantly higher on the Hogan Grief Reaction Checklist ($p = 0.00$) (Hogan, Greenfield & Schmidt, 2001), the Inventory of Complicated Grief ($p = 0.03$) and BSI-18 ($p = 0.00$) than the comparison group. This is most probably explained by the fact that they

had self-referred to the service, indicating a clear perception of need for support, while the comparison group had to be actively recruited, suggesting no such perception of need.

During the course of the study we found that the overall levels of distress in the intervention group had decreased significantly (Hogan Grief Reaction Checklist ($p < 0.00$), Inventory of Complicated Grief ($p = 0.00$), BSI-18 ($p = 0.00$)). On some of the measures (Inventory of Complicated Grief; BSI-18: subscale depression; HGRC: subscale despair) the levels had decreased at six-month follow-up to such an extent that they were comparable with the levels measured in the comparison group. By contrast, levels of distress reported by the comparison group remained relatively stable from baseline to follow-up.

While there is always the possibility – in the absence of a control group – that the intervention group would have improved anyway with the passage of time, the follow-up period in our study (six months) was quite short for such changes to have occurred naturally across this range of measures. Moreover, other intervention studies have reported similar reductions in pre- to post-intervention scores using the same measures as we used in our study (see, for example, Boelen *et al*, 2007).

Sampling, response and attrition rates

Sampling and response/attrition rates are also significant methodological concerns in most bereavement research designs. Most reviews of bereavement interventions suggest that the more complicated the grief process, the more likely it is that an intervention will yield positive results (Schut *et al*, 2001; Schut & Stroebe, 2005). These studies suggest further that the sampling and recruitment of participants may contribute, to some extent, to whether an intervention is found to be effective. For example, interventions targeted at the general population or those at risk tend to use samples that are actively recruited by the researcher (ie. participants do not self-refer to services), whereas interventions targeted at those with complicated grief tend to use samples of bereaved people who are actively seeking support. Thus, interventions targeting the latter tend to obtain more positive outcomes. Indeed, this was the case in our own evaluation of the one-to-one listening service, which found an association between the intervention and improvement in participants' overall levels of grief and psychological distress.

An additional significant challenge in evaluation research in bereavement support relates to the difficulty in achieving good response and low attrition rates. Response rates have been found to be typically low and highly variable in studies involving bereaved people (Stroebe & Stroebe, 1993). For the first phase of our evaluation we achieved a response rate of 47%, which compares favourably with other studies using similar methodologies (eg. 45% in Gallagher, Tracy & Millar, 2005; 40% in

Walsh, Foreman & Curry, 2007). In the second phase of the study, the great majority of intervention group participants who were contacted agreed to take part (93%). Other similar studies have reported response rates of 59% to 90% (Relf, 2000; Field *et al*, 2005). Unsurprisingly perhaps, the recruitment of the comparison group proved to be more difficult, with only 43% agreeing to participate. Other authors have noted similar difficulties in recruiting non-attenders in bereavement research (eg. Field *et al*, 2005).

The attrition rates in phase two of our study (10% and 11% for the intervention and comparison group, respectively) compare favourably with the 8–14% reported elsewhere (eg. Relf, 2000; Field *et al*, 2005). A number of factors may have influenced this.

Most indicated that they were participating because they wanted to help others, or to help the hospice

Participants' motivation to take part in our evaluation appeared to be predominantly altruistic, in that most indicated that they were participating because they wanted to help others, or to help the hospice. Others alluded to the strong rapport that had been established with the researcher at the baseline interview. In addition, there was some evidence to suggest that participants appreciated the willingness of the researcher to travel to their homes to conduct the interviews, as many people did not want to return to the hospice, or found it difficult to get there (this was particularly the case for the comparison group). Other researchers have also found that conducting interviews in the participant's home facilitates the process because the person finds the environment more emotionally comfortable and convenient (Hynson, Aroni & Sawyer, 2006).

Another feature of this study that may have facilitated the more favourable response and attrition rates is that the principal researcher (AR) was based in the hospice for three to four days a week during the course of the study. This meant that she became a familiar face within the hospice community, and was able to get to know the referral process to the bereavement support service, and formed positive and trusting relationships with the staff involved in processing referrals. Indeed, the hospice bereavement support staff agreed to add a further step to the referral process and ask those who were seeking support whether or not they would be happy to be contacted by the researcher. The researcher's presence in the hospice also meant she could attend referral meetings regularly, and follow up referrals promptly. She was also readily available to staff if they wished to raise any queries or concerns about the research process.

Identifying outcomes for investigation

Another methodological challenge in evaluation research involves the identification of appropriate measures. This applies as much to bereavement research as to other forms of applied research. Intervention studies in the bereavement field have been criticised for defining too narrowly the criteria used to assess the impact of the intervention, and for relying too heavily on psychiatric symptom checklists and/or global measures of functioning, which may not be capable of capturing relevant outcomes (Jordan & Neimeyer, 2003). In fact, Jordan and Niemeyer (2003) suggest that this may be why some studies do not find positive effects from interventions.

They argue that a broad range of outcome measures going beyond symptom assessment should be used in this kind of research. It is also important that these measures are sufficiently sensitive to both positive (eg. personal growth) and negative aspects of the grief response (eg. feelings of guilt and remorse). Although many studies are increasingly using grief-specific measures – as opposed to measuring health outcomes alone – use of measures of positive outcomes is still considered rare (Boelen *et al*, 2007; Kang & Yoo, 2007).

The path to obtaining ethical approval for studies in the field of bereavement (and palliative) care is rarely smooth

For this reason, we selected a broad range of widely used and well known measures for our evaluation including, in particular, those that are able to capture change over time and focus on both negative and positive aspects of the grief response (eg. yearning for the deceased, personal growth and self-efficacy). We also sought measures that were brief and psychometrically sound. The outcomes assessed were all considered in the literature to be central to this kind of research. They included grief reaction; complicated grief; mental and physical health; coping styles; perceived social support; alcohol use; self-efficacy, and help-seeking behaviours (see Table 1).

We used such a wide variety of measures in order to obtain a broad range of outcomes, but completing such a battery of questionnaires sometimes proved laborious for participants. Researchers may need to balance their desire to conduct as comprehensive and detailed an assessment as possible with an awareness of the demands that the completion of so many measures may place on participants. In our interviews, we made sure participants knew they could take breaks if they needed to.

Engaging stakeholders

Relationships with practitioners can be difficult when conducting scientific research (see, for example, Newsom *et al*, this issue). We were aware of the importance of developing and maintaining positive relationships with hospice management and staff, to ensure that they were open and positive towards the research process, rather than closed and defensive. One important factor was that the management of the hospice had actively sought to have the bereavement service evaluated and the study received prompt approval from the hospice ethics committee.

We also sought to involve staff as much as possible in the evaluation process. For example, a senior staff member was included in the steering group, as was a representative from a major organisation in the bereavement field in Ireland, which was also funding the research. The principal researcher also attended the hospice bereavement service staff meetings. These gave the study greater visibility and credibility with the hospice staff and helped to promote their involvement in and ownership of the research process. It also ensured they had access to first-hand information on how the evaluation was being conducted.

These positive relationships with the hospice staff also facilitated participant recruitment. For example, the researcher was given permission to access the hospice database and the staff were happy to explain the project to prospective participants. Furthermore, the staff appeared to be genuinely interested in the evaluation findings when they became available and the feedback and information sessions delivered at the hospice by the principal researcher were all well attended and well received.

Impact on participants

However, the path to obtaining ethical approval for studies in the field of bereavement (and palliative) care is rarely smooth. Many professionals working in, or associated with, the field of bereavement have concerns about a potentially negative impact of taking part in bereavement research. This concern, while understandable and well-intentioned, often presents a barrier to recruiting participants (Parkes, 1995). Ethics committees often assume that research studies with bereaved people will compound what is already a very difficult situation (Parkes, 1995). However, this kind of research can often be beneficial for the participants, and by no means necessarily causes harm (Cook & Bosley, 1995; Dyregrov, 2004).

We were also mindful, when conducting the interviews, that signs of distress in a participant may not always be negative. Numerous studies have reported that, even if participants become upset during research interviews, most find it to be a positive and helpful experience (eg. Brabin & Berah, 1995; Seamark *et al*, 2000; Contro, Larson & Scofield, 2002; Scott, Valery & Boyle, 2002).

Similarly, Cook and Bosley (1995) and Dyregrov (2004) found that not only do participants generally rate their experience of taking part in research as positive; they also derive benefit as they feel their participation in this kind of research is helpful to others. Many, despite their distress, value the opportunity to tell their story, share their feelings and obtain some insight into their loss (Cook & Bosley, 1995). They may obtain enormous therapeutic benefit from talking with someone who takes their stories seriously and witnesses and acknowledges their pain (Rosenblatt, 1995).

Indeed, this was true for the great majority of the participants in our study. Many reported that, although they found the interview upsetting at times, they also found it helpful. For example, a common theme in the participant interviews was the comfort they derived from knowing that others also experienced the symptoms listed in the research measures (eg. headaches, poor concentration), as they had been concerned that they were alone in having these reactions to their loss.

We implemented a clear protocol for the conduct of the interviews, in order to minimise any potentially negative impact on participants. From the outset, participants were informed that some of the questions might be quite difficult for them and that they could stop the interview at any time. The interviews were conducted with the utmost sensitivity. The schedules were semi-structured, and all participants were given sufficient time to talk about their experience of bereavement and their deceased relative/friend if they wished. Typically, interviews lasted an hour and, in the case of home-based interviews, often involved numerous cups of tea and preliminary chats.

Some participants did indeed become upset during the interviews. When this happened, they were treated with compassion and empathy and reminded that they could stop the interview at any time, or withdraw from the research altogether. A hospice-based social worker was available to offer support if required to those who participated in interviews at the hospice. The hospice's head social worker was also available by phone in the case of interviews conducted outside the hospice. At the end of each interview, participants were thanked for their participation and encouraged to contact the researcher and/ or the social work department if they wished. A thank-you card was sent to participants within a few days of the interview, and this also reminded them that they could contact the researcher or the hospice social work team at any time (none of the participants asked for this help).

The role of the researcher

The skills and qualities of the applied researcher are paramount to successful research with all vulnerable populations. Hynson and colleagues (2006) have outlined the key qualities to securing the engagement of participants.

These include an ability to show understanding without claiming to have any particular insight into participants' experiences; a capacity to cope with powerful expressions of emotion, and an ability to pace the interviews. Also important is being able to conduct the interview in an informal, conversational and non-clinical way.

The impact on the researcher of conducting a series of long, sometimes emotive interviews must also be considered

Throughout the interviews, the lead researcher sought to maintain a compassionate, empathetic, understanding and professional approach, and be mindful of the qualities that have been identified as important in securing the engagement of participants.

Although some of the measures were for self-completion, it was decided that they should all be administered face-to-face, due to the potentially distressing nature of some of the questions. This approach allowed the researcher to gauge any potentially negative impact on interviewees.

Flexibility was also clearly very important for the successful recruitment and retention of participants. As previously explained, many of the participants preferred to be interviewed in their own homes at the baseline interview (intervention group 28%; comparison group 86%), and these numbers increased at follow-up (intervention group 55%; comparison group 97%). This was often because they were reluctant to return to the hospice, and because it was more comfortable and convenient. However it was much more time-consuming for the researcher, both in terms of travel and the length of interviews, which tended to be considerably longer than those conducted in the hospice. But those interviewed in their own home were more likely to tell their bereavement 'story', to show and discuss photographs of the deceased and to engage in casual conversation over a cup of tea or coffee. All of this helped to establish a strong rapport between the researcher and participants. This suggests it is important to factor in this additional time, especially if a large number of interviews is planned.

The impact on the researcher of conducting a series of long, sometimes emotive interviews must also be considered. This aspect of research with vulnerable populations is often overlooked; ethics committees rarely consider the welfare of the researcher as they are principally concerned with safeguarding the research participants. The researcher may be highly sensitive to, and deeply affected by, the emotional pain of participants. It is considered best

practice for counsellors to arrange regular professional supervision in order to reflect on their practice and receive emotional support when required (British Psychological Society, 2005; British Association for Counselling and Psychotherapy, 2010). Rolls and Relf (2006) propose a form of professional supervision for researchers – the 'bracketing interview', which offers a research-focused supportive relationship to researchers.

In our study, supportive structures were put in place to ensure the health, safety and well-being of the researcher. Standard procedures for safe working practice in psychological research and guidelines for lone workers were followed for the interviews that took place in participants' homes (Department of Psychology, NUI Maynooth, 2007). In addition, the researcher received regular supervision from one of the research advisers (a social worker and a member of the research steering group) who was based at the hospice, and she met regularly with her research supervisor. This supervision time allowed the researcher to discuss the impact of the interviews and manage more effectively any potentially stressful or distressing effects of the fieldwork.

Benefits of evaluation

Although bereavement support is widely regarded as an integral component of a palliative care service, there is little consensus about the nature of these services and how they should be delivered (Field *et al*, 2004). Service providers often differ with respect to their goals and the range of services they provide, and develop their own, often unique, approaches to bereavement care. While such services should, at least to some extent, reflect the nature and needs of the communities for whom they are developed, it is crucial that each service can also demonstrate its effectiveness for the population it serves (Thomas, Baker & Kassner, 2006).

The findings of our evaluation are encouraging, in that they suggest that the hospice bereavement support service is performing well. It is providing what is, in many respects, a good model of care with a range of options that appear to be meeting most of the needs of its clients. The results of the evaluation also provide useful insight into a number of key elements of bereavement support that seem to be working well together in this setting, as well as identifying areas for improvement in the targeting and delivery of these services.

Such findings are invaluable and they can be used to inform the development and improved operation of this service, and other similar palliative care bereavement services in Ireland and elsewhere. Encouragingly, this kind of research also sheds some scientific light on whether or not these interventions work (Schut, 2005), as we are ethically obliged to do (Parkes, 1995). However, more extensive and more methodologically rigorous research

in this area is needed to ensure that bereavement support programmes are operating at an optimal level and are meeting the needs of their clients in the most effective, sensitive and appropriate way.

Conclusion

This paper outlines some of the factors and processes that we consider to be central to the successful evaluation of any bereavement service. The full research process has been reported elsewhere (Roberts & McGilloway, 2008, 2010) and was not the focus of this article. Our aim here was to discuss a number of key methodological, practical and ethical challenges that we encountered during the evaluation process, and how we overcame them.

Other factors relevant to this discussion fell outside the scope of this article, including the process of applying to ethics committees and other research design issues, such as choosing appropriate research methods (ie. quantitative, qualitative or mixed approaches), use of independent researchers and the effects of self-selection bias.

It is our hope that other researchers who intend to embark on evaluating bereavement services, or who are about to undertake other forms of bereavement research, will benefit from our experience. It is important to conduct rigorous evaluation of bereavement services. It is equally important to disseminate the findings to a wide range of audiences using media that are accessible to researchers and practitioners alike, in order to inform the development both of effective and acceptable bereavement services and the methods that researchers use to evaluate them.■

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