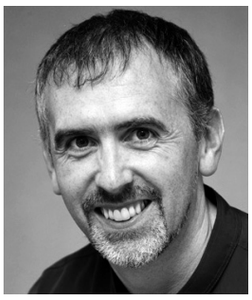
Evaluating a creative arts bereavement support intervention

Innovation and rigour



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Abstract: This article describes the evaluation of an innovative bereavement support group established in a hospice setting. The design of the group sessions was informed by the Dual Process Model and combined a range of creative arts activities with psycho-education. Evaluation was undertaken in two stages. An initial pilot group was evaluated informally, using participant questionnaires. The success of this pilot led to two further groups that have been evaluated in a randomised controlled trial, the results of which will be published in due course. This article explores some of the issues and dilemmas raised by evaluation in this context and discusses the importance of evaluation to developing a sound evidence base for innovative bereavement support work.

Keywords: Creative arts, psycho-education, evaluation, randomised controlled trial, hospice

St Francis Hospice (SFH) is a voluntary organisation offering specialist palliative care to people in North Dublin, and support to their families and friends. The hospice provides a community palliative care service, a hospice day care service and a 19-bed inpatient unit. Bereavement support is part of the continuum of care offered to families and friends of patients. The objective to 'further develop bereavement support services' was included in its 2007–2011 strategic plan.

The Irish Hospice Foundation (IHF) is a national charity that supports the development of hospice and palliative care, including bereavement care, in Ireland. It actively promotes the development and dissemination of innovations in education, training and service provision in the area of bereavement care.

The IHF and SFH were keen to explore options for developing bereavement support group interventions. The IHF had received a number of enquiries from bereaved people who were having difficulty finding support groups. Most bereavement care available was on a one-to-one basis. SFH was also looking to develop and evaluate new bereavement interventions that could be incorporated into their current bereavement support services (Roberts & McGilloway, 2008).

The two authors – one a senior social worker in SFH and the other a dramatherapist working with IHF in training and development – were asked to explore the possibility of running a bereavement support group for relatives and friends of people who had died in SFH.

Bereavement support using creative arts

A range of bereavement support group interventions were explored (Kirk & McManus, 2002; Rogers, 2007; Pathways Hospice, 2008; Worden, 2009), including drop-ins and closed and open formats. Stock-Whitaker (1994) argues that the closed group format can help to provide a level of predictability and cohesiveness for participants.

Jordan and Neimeyer (2003, p782) suggest that interventions are most effective between six and 18 months post-bereavement. Bonanno and colleagues (2008, p287) propose that it takes between one and two years for people to recover from acute bereavement distress.

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There has been an increasing awareness of the healing potential of creative arts methods of expression in general healthcare (Cohen, 2006; Daykin, McClean & Bunt, 2007; Anthony, 2008), as well as in bereavement care (Kirk & McManus, 2002; Bolton, 2008). As Rogers has written (2007, p7): 'The use of creative arts in a group setting facilitates a way of comprehending some of the most complex aspects of human existence and provides a structure for our emotional chaos and a shared social setting for the construction of meaning.'

Such methods of expression may enable participants to access and express their grief in different ways while, at the same time, providing a certain distance to that same grief. As Bolton (2008, p16) explains: 'The practice of an art offers reflective processes upon memories, hopes, fears, anxieties and angers without tackling these emotional states head on.'

The bereavement support group

The format chosen for the intervention was an eight-session, weekly bereavement support group that would offer creative arts activities and psycho-education.

The aim of the bereavement support group was to provide a safe and supportive experience where participants could use creative arts activities to express how they felt and receive psycho-educational information about grief, to reassure them that their feelings were normal (Thuen, 1995; Davies *et al*, 2007).

Through these interventions, it was hoped participants would be helped to:

- reduce feelings of isolation
- access support from others who have also experienced a recent loss
- explore different aspects of their grief and ways of expressing it
- access/develop their natural ability to oscillate between engaging with, and detaching from, their loss
- understand the normality of their experiences of grief, and
- access their creativity and to develop their own resources to cope with their experience of loss.

Each session would last one hour and a quarter, and the group would be facilitated by the two authors.

The creative activities chosen were based on the Dual Process Model of coping with loss (Stroebe & Schut, 1999), which suggests that healthy grieving involves oscillation between loss-coping (focusing on the person who died) and restoration-coping (focusing on rebuilding life following the loss). The activities were designed to help participants regulate this movement between focusing on their loss and detaching from it, in order to promote natural processing and integration of grief:

> 'Integration of the loss seems to occur through a process of oscillating attention toward and away from thoughts and memories of the deceased' (Shear *et al*, 2007, p458).

Activities such as telling the story of the loss or bringing in mementos of the person who has died are examples of facilitated loss-oriented coping. Creating artwork or memory jars or working with parts of a script or play about death – Shakespeare's play *Macbeth*, for example, or *Dolly West's Kitchen* (McGuinness, 1999) – are examples of restoration-coping as they enable participants to distance themselves from their own bereavement and look at how others have come to terms with loss and death (see box).

Memento space for telling the story of the loss

A memento space involves inviting participants to bring to the group session a memento that reminds them of the deceased person. Examples have included photographs, keys, shoes and even a syringe driver case. The group then creates a special space in the room, around which the mementoes are arranged. Each person in turn then explains the significance of their memento to the other members of the group. All the group members then move around the created space in silence and look at the mementoes. Finally, members share their experiences of the memento space. (Adapted from *The Mourning After* program (Pathways Hospice, 2008))

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Memory jars

For this groupwork activity participants each fill a jar, creating different layers using salt coloured with chalk. Each layer represents a memory of the person who died and of the creator's own grief journey. The participants can use the chalks to change the colour of the salt to one that represents a different memory.
(Adapted from Stokes & Crossley, 2007)

The participants

The group was run in spring 2009. Because this was a new, pilot initiative within the hospice service, it was decided to use a targeted approach for recruiting potential participants. The group was designed to be a level 2 bereavement care intervention, as described in the NICE (2008) guidelines on supportive and palliative care.

A number of possible participants were identified by the hospice social workers. It was decided to hold an information evening (two hours) to explain the purpose of the group to the potential participants (eight in total) and to give the facilitators an opportunity to assess their suitability for participation. Six people attended the information evening, of whom five decided to move on to the eight-session group. Two others were unable to make the information evening but, after follow-up phone contact, decided to participate in the group. However, one of these people found being in a group quite difficult and, in consultation with the facilitators, decided to leave after the second session. The other came for one session but decided not to continue with the group because of a family crisis.

Thus, out of an initial cohort of seven participants, five people completed all eight sessions. The facilitators would have liked a larger number of participants in the group, but it was decided that there were enough to run the intervention, given that it was a pilot project.

Evaluation dilemmas

Jordan and Neimeyer (2003) point out that bereavement care practitioners cannot assume that their efforts are necessarily helpful to people who are bereaved. In particular they note the paucity of evidence on the effectiveness of group bereavement interventions. Maruyama and Atencio (2008) echo this caution and argue for the use of validated, reliable measurement instruments and robust quantitative research designs such as, for example, those that include comparison groups.

However, Loughran and Kavanagh (2005), writing about social work research, highlight a tension between developing evidence-based practice and the need to maintain the flexibility required to explore innovative practice. If there is too little evaluation, valuable insights may be lost and, more importantly, the actual impact on bereaved participants cannot be assessed effectively. However, the demands of robust quantitative methods may place too great a burden both on the participants and on the bereavement service.

A staged approach

For this reason, SFH and IHF decided on a staged approach to evaluation. The initial pilot group intervention would be evaluated in a flexible way, using primarily qualitative methods and involving simply the participants, the hospice service and the group facilitators. Then, depending on the outcome of this evaluation, more structured methods would be developed to evaluate any subsequent groups.

Stage 1 – evaluating the pilot intervention

The main purpose of the pilot group was to explore whether a bereavement support group using creative arts was acceptable to bereaved people and had the potential to be an effective intervention.

Three main informant groups were identified:

1 the **participants**, to discover whether they believed the group helped them with their grief, and, if so, how
2 the **hospice service**, to find out if the intervention should be resourced and become part of ongoing service provision, and
3 the **facilitators** – to find out what aspects they considered to be helpful and what improvements needed to be made.

Group participants

Feedback from participants

Peer support

'The group were a group of people I connected with almost at once. All were different age groups, male and female, who had lost different members of their family.'

'Being with other people in their grief and joining together in our sorrow.'

'Being able to talk about your grief and loss with people who know what you're going through (non-judgmental, the peace and understanding, the play which we done, spirituality).'

Creative arts as a means of expression

'The concept of creativity as a means of expression I found enormously helpful.'

'I was not sure about the function of the drama but it was a lot of fun.'

'I have learned to be more expressive and allow myself to feel sorry and sad whenever I want to – tried to shut grief off.'

Increased confidence

'I don't feel so alone and lost, it has made me feel stronger and I feel we have united like friends when you most need a friend.'

'It has helped me bear the loss.'

'It has helped me to realise it's okay to be happy and not feel guilty, opened up and allowed me to speak about the loss and the sadness of my best friend my mam.'

A customised questionnaire was used that focused on the participants' experience of the group and their own grief. Feedback was sought from all seven participants, but the two members who did not complete the eight sessions did not return the evaluation forms. The overall feedback from the five participants who completed the eight sessions was positive and reflected some of the project's aims of reducing isolation, receiving support, exploring their loss and accessing their creativity. Examples of feedback from participants are given in the box below, grouped under the three themes of peer support, creative arts as a means of expression, and increased confidence.

Hospice service evaluation

The hospice service evaluation comprised regular review meetings with the head of the SFH social work department and a review with the head of research and education at the IHF. The key points that emerged from these reviews were:

- the eight-session group using creative arts was acceptable to participants and was perceived to be a helpful intervention by those who attended
- the pilot project indicated possible benefits from the group format and the hospice would consider offering that type of group again. However, further research would be needed to evaluate the effectiveness of the group
- the pilot intervention involved significant time and resources. Future groups would need careful planning around the availability of resources. (As Machin (2010) argues, policy and economic pressures have to be negotiated when looking at the delivery of bereavement care services)
- a more structured approach would be used to evaluate future groups, developing from a description of experience to a test of outcome.

Facilitators' evaluation

The authors who facilitated the pilot support group used regular review meetings to evaluate the process and to consider what changes, if any, could be made to improve the group if it were it to be run again. The key conclusions from these meetings are outlined below.

It was agreed that the use of an information evening (two hours) to explain the purpose of the group to potential participants was essential, especially given the experience of the two members who did not complete the group intervention. Neither had attended the information night and, although the purpose of the group was explained to them in a subsequent phone call follow-up, both facilitators agreed that it would have been preferable to have first met all potential participants in person.

It was agreed that restricting participation in the group to only one member of a family was a positive decision, as it enabled participants to explore their experience of their family and their grief more freely.

The length of the sessions could be increased to one and a half hours in future interventions. This would allow more time for participants to complete the activities and ensure that sessions would not be rushed.

Overall conclusions

The participants who completed all eight sessions evaluated the pilot group positively, although two participants dropped out after attending just one session. The facilitators also evaluated the pilot group positively, although there were aspects that they felt could be improved – in particular, the prior screening of participants to ensure that they would benefit from the group. The facilitators felt that the intervention had potential and could be run again. The hospice service agreed with these conclusions and was willing for the group to be run again and evaluated more formally, to develop an evidence base.

Stage 2 – developing an evidence base

Jordan and Neimeyer (2003, p765) point out that reviews of bereavement interventions suggest that they may be surprisingly ineffective, even though most grief support practitioners would argue that bereaved people benefit from their services. Thus, there may be a gap between the perceptions of researchers who are evaluating interventions with bereaved people and practitioners who directly provide services. Maruyama and Atencio (2008) argue that differences in the formats of bereavement interventions (eg. leaders, duration, open or closed groups) as well as weaknesses in study design (small sample sizes, lack of randomisation and controls) can contribute to this gap.

SFH and IHF therefore agreed to run the bereavement support group again in spring 2010, but this time as a formal research project using a robust randomised control trial design and established grief measurement instruments.

The participants were identified by SFH social workers through their contacts with relatives before or following the death of the hospice patient. This meant participants were all people who were already identified as possibly in need of or likely to benefit from support, and that they were open to receiving support. This is consistent with Jordan and Neimeyer's observation that people who are 'manifesting high-distress grief' are more likely to benefit from interventions (2003, p783).

As before, the evaluation focused on the three key groups – participants, the hospice service and the facilitators, with the main focus of the evaluation on the participants.

Potential difficulties

One of the potential difficulties involved in this type of research is sample size. The larger the sample size, the better the potential for discovering statistically significant findings. On the other hand, there is a limit to the number of people who can participate in this type of group and similarly limited resources available in the hospice service to run the project. Campbell and colleagues (2000) give some guidance on complex interventions and how they may be assessed initially using small samples.

Another difficulty involves the use of a control group. Is it ethical to ask people who may need support to wait for a period of time before they receive their intervention? This was overcome by offering participants in the control group the usual range of support provided by the hospice bereavement service while they waited to join the support group. If a participant used any of these services in the interim, they could still join the group but would not be included in the study.

A further difficulty arose in relation to evaluating the effectiveness of the creative modes of expression used in the group intervention. A wide range of expressive arts was used, including drawing, photography and drama as well as the memento spaces and memory jars described above. It was difficult to find one instrument that could measure the impact of all these interventions, so some form of qualitative evaluation was also required.

Research design

To evaluate the groups, a randomised waiting list control design was adopted, involving an intervention and a control group. Two grief measurement instruments were administered at three time points (see Figure 1 below). Both groups were evaluated, excluding any participants who had used bereavement support in the interim. The Texas Revised Inventory of Grief (TRIG) (Faschingbauer, 1981) was used to measure the impact of the group work on grief distress, and the Adult Attitude to Grief (AAG) scale (Machin, 2009) was used to measure the impact of the group on responses to loss.

Data were collected at the three time points to assess the grief reactions of respondents and, in particular, to ascertain any differences between the two groups. An independent researcher collected and analysed the data.

A customised service evaluation questionnaire was also administered by post at the end of each support group intervention. This provided qualitative information on the use of the creative modes of expression and information for the hospice service and the facilitators.

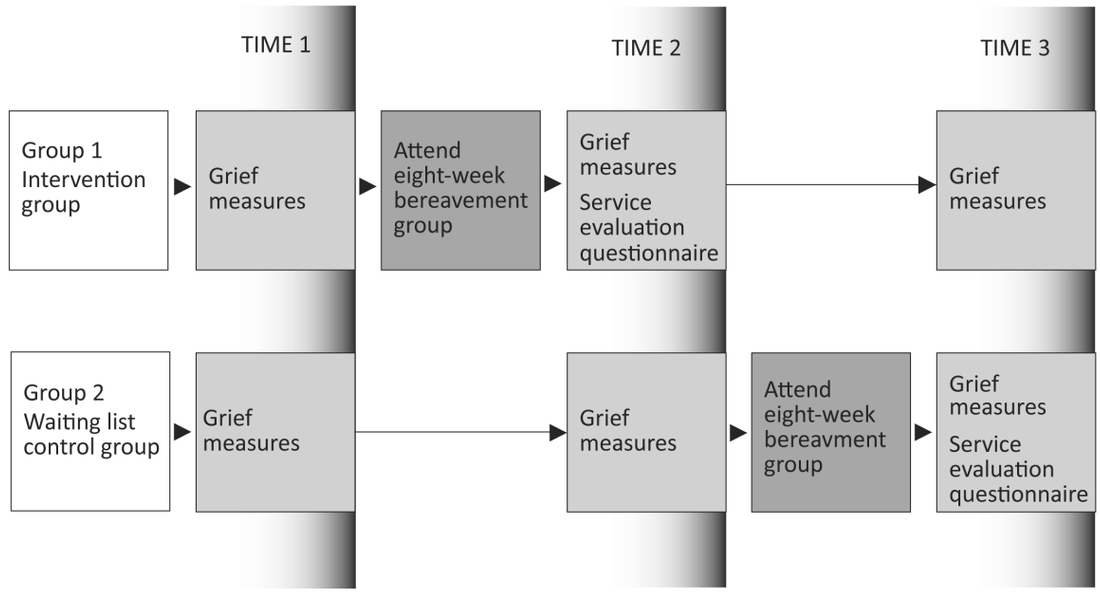
As before, the hospice service and the facilitators used a series of review meetings at different points in the research project to evaluate progress and the overall effectiveness of the group intervention.

The group interventions in the research project have now been completed and the results are currently being analysed and will be published in future.

Conclusions

Evaluation is key both to supporting innovative bereavement care practice and to developing an evidence base of effectiveness. This is necessary for any bereavement intervention and especially where that intervention may involve elements that are by their nature more difficult to evaluate (ie. creative arts).

Figure 1: Administration of study instruments



This paper has described a small-scale project to evaluate an innovative bereavement support group using creative arts, and the ethical and practical issues this raised. The staged approach successfully allowed these difficulties to be identified and explored at pilot stage, in order to inform the subsequent second stage evaluation in a formal, randomised controlled trial.

The project has demonstrated the importance of supportive organisations that are prepared to resource innovative practice and its evaluation in order to contribute to the developing evidence base for bereavement support work.

It also demonstrates the need for both flexibility and rigour on the part of those involved: the flexibility to contemplate innovative practice developments, and rigour to ensure they are formally evaluated using recognised instruments. It is also important that the data are disseminated to add to our understanding of what works in bereavement support, how, why and for whom.

Last, it shows that such innovative interventions can be evaluated using scientifically validated measures, despite limited resources, and on a relatively small scale, and still contribute useful data to the evidence base. ■

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