A retrospective records audit of bereaved carers’ groups

Rob Finley¹ and Malcolm Payne²

Abstract: Research on the effectiveness of groupwork for bereaved people in reducing symptoms of grief, is mixed, but many bereavement services in the UK offer support groups as part of their service. Information about the running and content of groups is mainly based on practitioners’ accounts of their experiences. An evaluation of groups organised in a large hospice and associated carers’ groups for 70 bereaved carers was undertaken by an independent retrospective review. This covered 65 records of group meetings and 22 evaluation forms completed by group members at reunions. The outcomes of this study contribute further qualitative information about the themes discussed by group members and arrangements for running such groups. Groupwork focused on the death as a shared difficult experience in their lives. 34 discussion themes in the groups were identified from the records, the most frequently discussed themes were family life, stories of the dying process and loss and loneliness. Facilitators’ assessments of the dominant mood in groups were analysed. Sadness was predominant. The group function in most groups was supportive. Members’ evaluations were mostly favourable. They valued meeting others and experiencing shared feelings.

Key words:

1. Groupworker
2. Policy and Development Advisor

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Introduction

While groupwork is an established practice in palliative care, there is little published information about the organisation and content of groupwork interventions in these settings, although a number of accounts of groupwork exist. This paper aims to contribute more qualitative information about the subject matter and mood of such groups to assist practitioners in running such groups. It offers a detailed account and evaluation of the setting up and functioning of groups for bereaved carers associated with a south London hospice and in carers' organisations linked to the hospice. The hospice had experience of various kinds of groupwork. This included activity groups with patients (Payne et al, 2008; Hartley and Payne, 2008), discussion groups providing mutual support with patients (Kraus, 1998), groupwork with children bereaved of a parent (Baulkwill, 1998), education groups on practical matters (Bechelet et al, 2008) and groups with carers during the dying phase (Harding et al, 2004). Carers' organisations had sought the support of the hospice in enabling their volunteers to experience working with bereaved people.

Groupwork is an established aspect of palliative care practice, with two main aims, psychological or social therapy and support (Sutton and Leichty, 2004). Firth (2005) suggests that a wide range of groupwork is practised in palliative care, including:

- Self-help groups, where patients support each other calling on the trust that develops from sharing similar experiences
- Children's groups
- Groups for bereaved adults
- Groups for cancer patients
- Client or service-user groups, to enable them to participate in service planning and feedback on their own experiences.

Carer groups

Field et al's (2004) survey of specialist palliative care bereavement services found that providing support groups was an activity in 63% of services, although this was less common in the US. Parkes (1996,
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pp.185-6), in an authoritative text, suggests that in the first few months after a death, few bereaved people wish to join groups, that research on the value of groupwork with bereaved people has been inconclusive, and that the main focus of groupwork should be practical and social support. The research manual informing the National Institute for Clinical Excellence guidance on palliative and supportive care (Gysels and Higginson, 2004) reports a number of studies on groupwork with carers, with no firm evidence about an appropriate model of practice. There was also little evidence about whether groupwork was an effective form of support in bereavement, although there are some well-conducted studies that show that self-help groups demonstrate some benefits. Take-up of groupwork is low (Gysels and Higginson, 2004).

A variety of objectives, structures and programmes for groupwork are described in the professional palliative social work literature (Oliviere et al, 1998, ch 4; Sutton and Leichty, 2004) and technology-based groupwork, using telephone and online systems has also developed (Colón, 2004). Accounts based on experience suggest that both structured, time-limited and unstructured, open-ended groups can be helpful to carers (Sutton and Leichty, 2004; Walter, 2005; Reith and Payne, 2009). This literature also suggests that careful planning is required to establish objectives, ground rules for behaviour in the group, referrals and selection of group members, leadership, practical resources and liaison with staff and volunteers referring potential group members (Oliviere et al, 1998, ch 4; Sutton and Leichty, 2004).

One well-constructed independent evaluation supported time-limited groups with a structured programme as helpful to carers with active caring responsibilities (Harding et al, 2004); it is not clear that such a model would necessarily transfer to the different position of bereaved carers, who might have different needs.

Reflecting this research and professional commentary within palliative care, the groups that were evaluated in the present study were designed as mutual-support groups for bereaved adults who had been carers. Children were not supported by this project, since bereavement care for children is organised through another hospice project. Reith and Payne (2009, pp.197-198) suggest that groupwork in palliative care has the following potential purposes, to:

- Assist people to deal with emotional and cognitive issues
• Offer information and practical assistance
• Enable people to take part in activities that achieve fulfilling experiences for them
• Enable people to have spiritual guidance and reflection.

The main objectives of these groups were considered to be the first two, achieved through sharing of mutual experience, although the latter two objectives were not excluded.

This paper describes first, the model for running the groups, then reports an independent analysis of the records maintained by the groupworker to identify themes raised and the progress of the groups. Finally, there is a report of evaluations by group members received in questionnaire in reunions organised by the groups.

**Running the groups**

Lund et al (1989) report a study that identified a number of difficulties in setting up and running bereavement self-help groups with mixed professional and non-professional leadership. This included problems with identifying, training and supervising group leaders, finding group meeting sites and the need for detailed advance planning. The hospice and carers project tried to resolve issues such as this by being prepared to be flexible with its planned format of having eight meetings of each group to address the practical problems of people’s lives. Younger bereaved people with children in particular found regular attendance difficult to organise and not all group members had well-organised family lives. Therefore, some groups had a shorter life than eight sessions, and some irregular attendance was accepted as inevitable, although group members appreciated knowing the reasons for absence and receiving apologies in advance.

The importance given to careful advance planning in the professional literature led to consultation about systems for referral and support for these groups. Self-referrals to the in-Hospice groups were sought through a general system drawn from the experience of the Michael Sobell House Hospice in Oxford, as follows. Patients accepted from home or in-patient care by the hospice are asked to designate a ‘next of kin’. The project wrote to all next of kin six months after the loss, after...
the period in which people may be reluctant to join a group. Those interested returned a reply slip, and were contacted for a telephone discussion by the groupworker. When there were enough people on the waiting list to constitute a group they were contacted again and a weekly session time decided that suited the majority of participants.

In addition to self-referrals, social workers and bereavement support volunteers (bsv) were invited to refer bereaved clients who had completed their individual work and wanted to take part in a group. If sufficient referrals and self-referrals were received, groups were set up for sub-groups of bereaved people according to their relationship with the deceased person; for example, while most groups were of bereaved spouses, there were two bereaved adult sons and daughters groups and one group specially for ‘older’ spouses, that is all the members were over 65 years of age. The groupworker facilitated the groups with one bsv from the hospice or a volunteer from a carers organisation; a pool of three bsv were interested in participating and received initial training from the groupworker.

A typical group ran for eight sessions of two hours; members were invited to arrive 15 minutes early for refreshments. The groups had a pre-arranged structure of topics, see Figure 1 overleaf. These were intended to act only as a springboard for discussion. This format was truncated for some groups, depending on the availability of bereaved carers, particularly with the community organisations, where carers wanted shorter programmes of groupwork. As well as general discussion in the groups, written exercises and pair discussion are also occasionally used. Although primarily support groups, the structure and educative emphasis helped to engage members by reducing anxiety and fearfulness about what the groups would be like.

An important factor in the hospice’s thinking about the aims of the group was the group psychotherapy concept of ‘universality’, helping a participant to know that they are not alone and isolated with unique issues. The basis of this idea is that simply being in a group setting, amongst individuals who have similar issues to your own, can be healing in itself (Yalom, 2005) When group members are accepted by other members despite the weaknesses they feel they have, their feelings of shame and isolation begin to fall away. Also, knowing that there is a universality of human experience and emotion can provide a sense of connection, reducing feelings of isolation.
The groupworker’s report on the running of the first groups stated: ‘groups bond well during the middle phase of the eight week programme but often rediscover dissimilarities as the groups end, for instance noticing differences in their grieving styles. This was considered a healthy step in the dissolution of the group and a recognition that the process had ended. Sometimes, however, members continued to find similarities between each other in experience and character. There was a strong chemistry between the individuals and some formed friendships that were sustained. Several groups asked to have a reunion some weeks or months after the ending of the programme, some meeting monthly for two years afterwards’.

Figure 1. Group programme, bereavement groups for carers and spouses

New Horizons Group Programme

Session One- Introduction  
Session Two- Reactions to Grief 
How it affects you now. What are the stages you might go through?
Session Three- Stress 
Taking care of yourself 
Session Four- Relationships 
Friends and family. Are things different now?
Session Five- Anger and Guilt 
Do you feel you blame yourself or others? 
Do you feel angry about things but wish you didn’t?
Session Six- The Story 
Using mementos or photos, we hear your anecdotes and stories about your lives together.
(This is led by Jan Lenton based on techniques of storytelling. Jan is a Principal Social Worker, Counsellor and Storyteller)
Session Seven- Coping well 
Would you like to deal with this better?
Session Eight- Goodbye for now 
What next from here?

The sessions will involve:
- open discussion
- discussion guided by facilitators
- some use of written exercises
- handouts with written material
- suggesting that you keep a journal/personal diary over the coming months. This helps people keep abreast of the peaks and troughs of their experiences

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This request for a reunion by early groups led to the idea being suggested to later groups and it was widely adopted. Participants return for a one-off reunion group offered a useful place to share successes and renew contact. At this time, members were asked to complete evaluation forms and provide verbal feedback on what was useful about the groups, to help practitioners make further improvements in the groups. In his study of groupwork with older bereaved spouses, Lund et al (1989) tried to prevent informal meetings such as this outside groups, unsuccessfully, and it seems that groupworkers need to make provision for such possibilities in their planning.

The groupworker conceived the role of facilitators as being to act as a container for group feelings and 'to steer from the back seat', feeling that the role is being well-executed if methods of conducting the sessions are invisible to members. Where it emerged in a group meeting that a member’s grief was complex or disturbing, the bereaved carer was sometimes referred to the bereavement service coordinator for further individual work. Experience of these groups confirms the view expressed in the literature discussed above that a psychotherapeutic focus on treating emotional difficulties is inappropriate in a support group context. To preserve the experience of universality, people needed to be able to share similar experiences of grief.

Evaluation methods

The overall project was evaluated as part of the hospice’s audit programme by its Policy and Development Adviser, making use of available records; no additional information was sought from group members. Analysis of records by someone unconnected with the running of the groups, and the collection of anonymous evaluations by group members sought to reduce any bias arising from the practitioner’s involvement in the evaluation. Retrospective analysis also focuses on the evaluation of contemporaneous material, avoiding bias due to hindsight and faulty recollection. However, relying mainly on practitioners’ records and accounts of group process means that alternative perspectives are less influential than the practitioners’ on the evaluation. Reliance on written notes prepared for agency records reduces the richness of data, as compared with alternative methods such as, for example, viewing and independent analysis of audio or video recordings of groups. However,
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the methods chosen were adequate to provide data to inform evaluation of the overall success of the programme and provide information about themes dealt with in such groups.

Approval to conduct the analysis was given by the Hospice’s Research Committee, in accordance with its research governance procedures. Because it is an evaluation, research ethics approval was not required, but disclosure of personal data was avoided because the records used do not contain personal data that would enable individual group members to be identified. The groupworker was asked to write an account of the groupwork, which is the source of the section on running the groups, above. This paper focuses on the content and running of the groups.

**Analysis of records**

The project used a two-page format for practitioner recording of the groups, shown in Figure 2. A record according to this format was prepared by agreement between the facilitators at the end of each group session. This was intended to be a memory aid about topics covered in the discussion and contributions and information expressed by individual members that might help the facilitators work with continuity in following weeks.

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**Figure 2. Recording sheet**

<table>
<thead>
<tr>
<th><strong>Group recording sheet</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Date:</strong></td>
</tr>
<tr>
<td>Who was present?</td>
</tr>
<tr>
<td>What was discussed?</td>
</tr>
<tr>
<td>What was overall mood and feeling like?</td>
</tr>
<tr>
<td>Did the group function cohesively or were there power struggles, difficult dynamics or interpersonal issues?</td>
</tr>
<tr>
<td>How did the group end</td>
</tr>
<tr>
<td>Other comments</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

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Findings

Membership and attendance

Records for ten series of groups were inspected, attended by 70 people, 19 men and 51 women, an average of seven for each group, ranging from six to nine; the intention had been to achieve a group size of eight. There were records of 61 group sessions with a total of 291 attendances; the average attendance at a group was, therefore, 4.7, ranging from two to nine. Men were always in a minority, and two groups comprised only women. Four reunion records were added to these records of group sessions, making up the total of 65 records analysed.

Themes in discussions

The facilitators were the groupworker and the bsv or carers’ organisation volunteer. Their summaries of themes discussed in sessions in 65 recording sheets of groups, were analysed. Since the groups had been sent information in advance of topics that might be covered, it was thought that themes discussed might reflect this list, which had been created in consultation with several local practitioners who had experience of groupwork with bereaved people. In particular, facilitators felt that most final sessions would focus on the ending of the group and feelings about it. Moreover, it was possible that the facilitators, having created it, would use the terminology of this list. However, two themes in the list were not recorded and one was recorded only once, suggesting that the list did not have an unreasonable influence on topics discussed, and that topics were genuinely chosen by group members.

The analysis therefore started from the list, noting 11 themes mentioned in it. Other themes mentioned were coded in addition; themes mentioned only twice were aggregated where possible. Eventually, 34 themes actually recorded were listed in the Table 1, showing how many times particular themes were recorded. These were usually simply listed in one, two or three words, but occasionally more detail of the discussion was supplied. It appeared that this happened when the discussion was thoughtful and complex. On average, 4.06 themes were mentioned in each recording, ranging from zero (a disrupted meeting) to eight.

The analysis was checked by two experienced bereavement
### Table 1: Themes of group discussions recorded by facilitators

<table>
<thead>
<tr>
<th>Potential themes identified in the programme</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, supportiveness, demands of children, conflicts</td>
<td>25</td>
</tr>
<tr>
<td>Stories of dying process</td>
<td>22</td>
</tr>
<tr>
<td>Grief</td>
<td>15</td>
</tr>
<tr>
<td>Coping, sharing ways of coping, in one case proud of coping well</td>
<td>11</td>
</tr>
<tr>
<td>What next, future plans, moving on, looking to the future</td>
<td>10</td>
</tr>
<tr>
<td>Friends, their supportiveness, differences from relatives, and not being ‘so bereaved’</td>
<td>10</td>
</tr>
<tr>
<td>Anger</td>
<td>8</td>
</tr>
<tr>
<td>Guilt</td>
<td>9</td>
</tr>
<tr>
<td>Self-care</td>
<td>1</td>
</tr>
<tr>
<td>Goodbye</td>
<td>0</td>
</tr>
<tr>
<td>Stress</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Themes noted in the records</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss, feelings of, things lost</td>
<td>19</td>
</tr>
<tr>
<td>Loneliness</td>
<td>18</td>
</tr>
<tr>
<td>Practical issues, finance</td>
<td>14</td>
</tr>
<tr>
<td>Belongings of deceased person</td>
<td>10</td>
</tr>
<tr>
<td>Sharing photos, readings</td>
<td>10</td>
</tr>
<tr>
<td>Apathy, futility, lack of motivation</td>
<td>10</td>
</tr>
<tr>
<td>Talking about the lost person</td>
<td>11</td>
</tr>
<tr>
<td>Group ending</td>
<td>8</td>
</tr>
<tr>
<td>Independence, demands, pleasures, difficulties</td>
<td>8</td>
</tr>
<tr>
<td>Carers, being a carer, attitudes towards</td>
<td>7</td>
</tr>
<tr>
<td>Memorialisation, other rituals</td>
<td>6</td>
</tr>
<tr>
<td>Work</td>
<td>6</td>
</tr>
<tr>
<td>Pining</td>
<td>5</td>
</tr>
<tr>
<td>Time, passes quickly or slowly</td>
<td>5</td>
</tr>
<tr>
<td>Holidays</td>
<td>4</td>
</tr>
<tr>
<td>Group evaluation</td>
<td>4</td>
</tr>
<tr>
<td>Alienation from the modern world</td>
<td>3</td>
</tr>
<tr>
<td>Denial</td>
<td>3</td>
</tr>
<tr>
<td>Depression</td>
<td>3</td>
</tr>
<tr>
<td>Openness and talking to strangers</td>
<td>3</td>
</tr>
<tr>
<td>Life after death beliefs</td>
<td>2</td>
</tr>
<tr>
<td>Moving house</td>
<td>2</td>
</tr>
<tr>
<td>Should have died with partner</td>
<td>2</td>
</tr>
<tr>
<td>Affairs</td>
<td>1</td>
</tr>
</tbody>
</table>
counsellors unconnected with the project, and by the groupworker. The counsellors agreed that the topics identified in the analysis were typical of issues raised by bereaved people, which suggests that the recording is a reasonable representation of issues likely to be raised in such groups. The groupworker agreed that the analysis is an accurate representation of his recollection of the balance of topics discussed. Other accounts of themes raised in groupwork with bereaved people present similar lists. Walter (2005) drawing on the literature and her own experience lists: loneliness and isolation, identity change from we to I, relationships and intimacy, dealing with anniversaries and shared experiences and identifying appropriate rituals, handling anger and other negative reactions and taking responsibility for and care of oneself. While this listing of topics is phrased differently, it covers a similar range of topics.

The coding’s focus on the topics discussed does not always represent the richness of the discussion. For example, one sophisticated discussion coded simply as ‘family’ and ‘loneliness’ covered the following and includes a direct quotation from a group member:

Grandchildren and children: who resembles whom physically or in character? [This is] continuing the presence of the partner in some way. This leaves an ‘empty space around, not just physically, but inside your head’.

Another example of the weakness of the subject coding was the following record, coded ‘loneliness’:

Keep TV lights on, can’t bear silence; before it was OK. Habit of phoning/being phoned: being alone before was fun cos you can do what you like, now it gives you no pleasure.

While emotional reactions such as guilt or anger were often simply noted, at times there was a more nuanced discussion, in which an idea expressed in one situation, aroused comment about related situations:

Guilt: about children losing a parent whom they couldn’t replace; guilt about others’ grief (in-laws or friends who’d fallen out or been absent).

The apparently prosaic could also engage groups in a more complex
discussion. For example, in a discussion on the apparently routine topic of newly bereaved people choosing holidays, which arose several times in the groups, the following exchange represents different views about the value of a newly independent life against concern about being able to use the holiday as an opportunity for a new social life:

C. wants long independent travel; others either not interested but more [group members] worried they wouldn’t [be able to] socialise, so they wouldn’t enjoy it.

Discussion about family, as well as being pervasive, was multifaceted, sometimes being about the effects of grief in different kinds of relationships:

Comparing losses and relationships between mums and sons, dads and daughters, mothers and daughters, sons and fathers sharing or not sharing in grief.

Kids are great, but it’s not the same as a partner

Difficulties in relationships also emerged:

…similar experience of falling out/lack of bonds/distance with siblings where others couldn’t face the illness or talk about their feelings…

There were also comments about child care issues:

Appropriate boundaries for children (without pandering to their rebellion or exploiting unconscious anger: ‘why was it daddy and not you?’).

Finally, an occasional but notable area of discussion was coded as ‘alienation from the modern world’. The recordings that led to this coding are as follows:

Living life as it currently is, seeing the modern world with this scar of bereavement, more sensitive to bad news everywhere; admitted their perception is altered.

Feeling an alien in a fast moving techno world, being left behind, hence difficulty in being reintegrated into the working world.

Being vulnerable, open to attack, worry about anti-social behaviour in the mall.
Exchanging stories about tricksters, fraudsters and widow-hustlers. Potential to form an agoraphobic circle. Mistrust of people, everyone’s a cowboy. Manipulation by the media feeling on this, exploitation everywhere.

Mood

Another section of the record form asked facilitators to summarise ‘the overall mood and feeling’ of a group session. Each group recording, including such an assessment (n=44) was coded. Facilitators sometimes seem to have found it difficult to assess or to distinguish it from the separate category of group function. The assessed mood often reflects the facilitators’ overall view of the group’s functioning. Five recordings of one eight-session group, for example, mention reticence and tentativeness, and one four-session group focused on mutual support. Where there was one dominant mood mentioned it was sad, tearful or difficult 17; light, relaxed or upbeat 8; reflective, 7; supportive 6; angry or worried 3. Mood in the groups was sometimes mixed; in three sessions sadness or anger sometimes occurred alongside brighter or more humorous moments. This provides some evidence that inexperienced groupworkers do not need to fear that negative feeling will be hard to manage in a support group.

Group function

The changing mood of the groups was also reflected in the records of the group function, that is, how the members related to one another, and how they dealt with issues in the discussion. Summaries of the facilitators’ assessments in the 45 group recordings where they were available were divided into six categories, set out in Table 2. Most groups were supportive, reflected ordinary relationships in a group or were positive in other ways. A few groups had difficult moments.

An example of a struggle to deal with issues, then establishing useful discussion is as follows:

Direction was lacking at the beginning. The group resisted attempts to bring the themes forward. After diverting to a conversation about smoking, they moved on to donating body parts. Then deeper discussion, more intense about opportunities to say goodbye to their partner before death.
Group members would challenge each other:

*C and S are indifferent about their lives continuing and would not care if they died. J challenged if this meant C is depressed, although she ‘doesn’t think’ she is.*

Groups also progressed in their discussion. A later meeting of a group that had been slow to develop relationships was described as follows:

*A smooth flow of energy and dialogue. Pauses were no longer uncomfortable but instead facilitate reflection or thought.*

The record form provided for an account of group endings, but this was often not separately recorded, and an analysis yielded no useful information.

**Evaluation forms**

Because of the time delay until the reunions at which evaluation forms were completed, 22 forms were in the records at the audit stage, covering four groups. The forms asked six multiple choice questions. The total responses are set out in Table 3 overleaf. These indicate an almost wholly favourable response to the experience. A caution is that this
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may reflect a rosy glow of events weeks or months in the past, and the fact that people who stayed the course to the end and then on to the reunion may be more committed to the groups than people who did not attend. The only substantial objection, was in the only shorter, four-session, group that reached the reunion stage; and a third of attenders here thought the length of the group was too short and the number of sessions (almost the same issue) too few.

After these structured responses, group members were asked to write what was most and least helpful to them and were asked for any suggestions for improvement.

There were two non-responses to the question about what members found most helpful. Fourteen mentioned meeting others, six mentioned shared feelings, with three specifically mentioning grief, four mentioned having the same feelings as others, four being in the same situation as others, two mentioned not feeling alone or lonely, two being able to listen to others. Three mentioned the chance to take part in a social event out

Table 3 Evaluation form responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Alternatives</th>
<th>Number of responses</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group was</td>
<td>Helpful</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of group</td>
<td>Too short</td>
<td>3</td>
<td>All in the four-session group</td>
</tr>
<tr>
<td></td>
<td>Too long</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>About right</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Number of</td>
<td>Too few</td>
<td>4</td>
<td>Half in the four-session group</td>
</tr>
<tr>
<td>sessions</td>
<td>About right</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject Matter</td>
<td>What I needed</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not what I needed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non response</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>Convenient</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inconvenient</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non response</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Room was</td>
<td>Comfortable</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uncomfortable</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
of the house; this seemed to reflect a less ‘sharing’ and ‘feelings’ focused attitude than some other respondents. More individual comments validated the groupworker’s approach ‘laid-back but concerned’, another valued a meeting at which poems and paintings had been shared and a third the chance to share experiences about children.

There were eight non-responses to the question about what was least helpful plus three indications that there was no comment to be made, four saying that nothing was unhelpful or that everything was helpful. Most adverse comments were made about the first group series, where one respondent felt that ‘some people needed a more medical intervention’ and found the effects depressing, one felt that it was not a full group, probably due to absences, and one accepted responsibility for avoidance: ‘The fact that I kept ‘forgetting’ where I had to be on Wednesday evenings’. Two further comments in other groups were that one older person was disadvantaged by poor hearing and another commented on struggles with the tea and coffee pots, which we interpret as a positive comment.

Most people (n=13) had no suggestions for improvements. One from the first group sought a group more like a psychotherapy group, more formal in its style and ‘with a stronger confidentiality policy in place’. Another member of this group commented how interesting it would be to see what the follow-up group would reveal. In one group, two members would have preferred a more structured format with more interventions by the groupworker, for example: ‘when there were silences I would have liked the facilitator to have intervened more’, while two others supported a non-directive approach: for example: ‘I preferred the informality of the group and felt this helped to make us all more comfortable and contribute to the session’. This had clearly been an issue for this group. Comments from other groups included the suggestion of a day out to the seaside, a member seeking a group for people whose relative had died from a specific disease with its particular trajectory. And a comment on: ‘dress code: only cleanliness and tidiness of clothes is important’; this clearly emerged from some aspect of the group discussion.
Discussion

This paper describes a retrospective analysis by an independent evaluator of group records of a number of group meetings with bereaved carers in various relationships with a deceased person. It was part of a partnership project between a large hospice and local carers organisations to develop groups for bereaved carers in carers organisations. Carers organisations sought to cease work with carers if the person they were caring for died, but continuing contact with some carers suggested that there would be value in developing support, if required, during any period of bereavement.

The main aim was to provide groups that would assist people to deal with emotional and cognitive issues, by sharing experiences of the bereavement as a difficult phase in their lives, reducing isolation and increasing members’ acceptance of their feelings and thoughts as normal in the circumstances. Most groups were either four or eight two-hour sessions organised weekly. The aim had been, for practical reasons, to achieve a group membership of eight, and the groups averaged seven, with attendance averaging between four and five each week; this reflects the previous research that take-up of group experience is often low. Experience of groups after this evaluation where larger initial numbers up to twelve were practicable suggested that regular attendances of eight and above were usually attainable.

The bereaved carers needed to have moved on from high levels of distress. Two early series of groups were disrupted by members who needed individual help; these particular experiences led to many of the adverse comments made by group members in their evaluations and to more careful selection in later groups. This suggests that groupwork focused on bereavement may not be helpful or effective where group members experience serious wider issues in their lives. Only one four-session group was evaluated, but a high proportion of this group’s members expressed the need for more time, so longer timescales seem to be indicated for bereaved carers groups.

The recording format used included provision for noting attendance, the themes discussed, the overall mood, the group functioning and relationships and the ending (to assist facilitators to pick up the groups’ concerns later). Separately a note was made of the contributions and role in the group of each of its members. Users of the records over time
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seemed to have difficulty in disentangling the concepts of overall mood and group functioning, and did not use the ‘ending’ section very often. As experience developed, recording focused more on individual group members, rather than the group process.

The themes discussed in the groups covered a wide range, with family, stories of the death, loss and loneliness the most frequently mentioned. This paper aims to present a more extensive and qualitative impression of how these issues emerge in groups than is available in the literature. Among various practical issues, and concerns about establishing a life role that was not about caring, the difficulty of dealing with the belongings of the deceased person was a common experience. Since research evidence (Stroebe et al, 2007) suggests that many people do not need or seek bereavement support, and are able to make good use of information, the various topics identified may offer helpful ideas about additional information that bereaved carers might find useful.

One of the reasons for the project was to explore with carers’ organisations whether the emotional content of groups for bereaved carers would be too powerful for their volunteers to handle. For this reason, the facilitators’ assessment of the overall mood of the groups and the group function was important. Although many of the groups incorporated sadness, this was often relieved by reflective periods and periods of lightness. Except where group members had significant remaining emotional problems about their bereavement, therefore, the groups proved manageable, and, according to the evaluations, largely satisfying and useful for them. Therefore, organisations do not need to be concerned that a concentration of emotional reactions or unmanageable difficulties will occur in groups for bereaved carers so long as they are part of a wider service able to resolve important individual difficulties.

The recordings of the groups also documented insights into the experience of some bereaved carers. In particular, there was a sense of isolation and loneliness, unrelieved by families and friends, and difficulties in managing relationships with children, where carers were still in a parental role were most often discussed. Re-establishing work patterns was also an issue for younger carers, and this connected with wider feelings of apathy, futility and lack of motivation deriving from the bereavement. Sympathy from others, particularly strangers, did not help in dealing with these feelings. However, although stress was listed in the programme as a potential issue, group members defined their
feelings in terms of loss and loneliness rather than emotional or social pressures. Current social and work worlds seem to exclude bereaved carers from social reintegration after their period of caring, and this may be a useful focus for bereavement support work in many settings.

Conclusion

This evaluation of a project providing group support for bereaved carers indicates that such provision may be a useful part of other supportive activities. Organisations whose main focus was on helping carers found that concern that their volunteers would be unable to handle the emotional content of bereavement in such groups was unjustified. Evaluation by group members was positive, and the groups formed a useful additional contribution to the hospice bereavement provision for some people. The themes discussed assisted in the identification of areas of discussion that might usefully included in information provided to all bereaved people. Since research evidence is that most bereaved people mostly require information rather than support services, such groups provide for the needs of a minority, who may nevertheless value them as an adjunct or alternative to one-to-one counselling and support. The content of the group discussions reaffirms the sense of isolation and loneliness for some bereaved people, even where they have family and friendship networks.

References


