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Bereavement support in a hospice setting

The role of a bereavement information evening



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Abstract: Little attention has been paid to documenting the quality and effectiveness of hospice bereavement support programmes. This article reports findings from an evaluation of a bereavement information evening (BIE) that forms a part of the adult bereavement support service provided by a large hospice in Dublin. The findings indicate the usefulness of the BIE in providing mid-level support for people who may need more than an information leaflet but may not require more intensive one-to-one support, while also acting as a 'gateway' to more intensive bereavement services for those who find it difficult to ask for help. However, measures may need to be put in place to ensure those who are unable or do not wish to attend these kinds of events also receive information about the bereavement process. The data may also be useful to hospice bereavement support services in deciding how best to meet clients' varying levels of need.

Keywords: Bereavement support, information, hospice, drop-in, tiered model

The provision of support for people who have been bereaved is integral to the family-centred philosophy of palliative care (NHPCO, 2000; NACPC, 2001; NICE, 2004). Hospice-based bereavement support encompasses a wide range of services, including phone calls or home visits from hospice nurses, hospice memorial rituals, leaflets and other self-help materials (for example, on coping with bereavement), social activities, mutual-help groups, one-to-one counselling and therapeutic groups (see, for example, Lattanzi-Licht, 1989; Foliart, Clausen & Siljestrom, 2001; Demmer, 2003; Wilkes, 1993; Rolls & Payne, 2003; Field *et al*, 2004; Yi *et al*, 2006; Marquis, 1996; Matsushima, Akabayashi & Nishitateno, 2002). Such diversity reflects, perhaps, the widely varying levels of need among those who have been bereaved, from simple information about loss and grief through to referral to mental health services (NICE, 2004).

Tiered model

National guidance on bereavement care in Ireland and the UK recommends a three-tier (or component) model (NACPC, 2001; NICE, 2004). At tier one, services provide

information about grief and bereavement and how to access support. Services at tier two offer bereaved people a formal opportunity to reflect on and discuss their loss experience, either with a professional or volunteer bereavement support workers/befrienders, or with mutual-help groups and faith and community groups. There should also be a referral process to tier three services for people who present with complex needs and may need professional support. Services at tier three cater for those who require these more specialist interventions, such as mental health/psychological support services and specialist counselling/psychotherapy services (NICE, 2004).

The NACPC and NICE reports cited above recommend that all service providers should offer level-one support in the form of information about and sources of practical help for bereaved people. Typically, this kind of information is provided in written format, either directly at the hospice, or by post (Wilkes, 1993; Field *et al*, 2004, 2007).

A case study from Ireland

This article focuses on an evaluation of the bereavement information evening (BIE) offered at a hospice in Dublin,

Ireland, as part of the support it provides to bereaved people. The study was part of a wider evaluation of the adult bereavement support service within the hospice commissioned by the Irish Hospice Foundation to help inform the future development of hospice services. The hospice is one of eight in Ireland and one of only three in Dublin. It provides in-patient care (19 beds), day care and home care to a catchment population of almost half a million (Northern Area Health Board, 2004).

The bereavement service provided by the hospice has a number of elements: a bereavement follow-up contact in the form of a post-death phone call/visit from a nurse; a monthly memorial ceremony (MMC); the bereavement information evening (BIE); a volunteer bereavement support service (VBSS) (a one-to-one listening service provided by trained volunteers); a counselling service; an annual remembrance service and an annual Christmas 'Tree of Life' ceremony.

Family and friends of patients who die in the care of the hospice are invited to attend a BIE, held at the hospice, approximately three to six months after the death. A social worker gives a talk about grief and bereavement and the support services available at the hospice and the attendees are then offered refreshments and the opportunity to talk to a social worker and some of the bereavement support service (VBSS) volunteers who work at the hospice. These kinds of information and drop-in events are quite unusual (see, for example, Wilkes, 1993; Field *et al*, 2004, 2007); most UK hospices provide one-to-one support as their main bereavement service. However, Walsh and colleagues (2008) found that most bereaved people welcomed an invitation to an annual public lecture on bereavement.

The study reported here was conducted principally to find out what participants thought about the BIE, its strengths and weaknesses (ie. the extent to which it is meeting stakeholder needs/objectives) and how it might develop in the future.

Method

A mixed-methods research model was used, comprising a cross-sectional postal survey and a small number of one-to-one interviews with bereaved clients.

All the families and friends of patients who had died in the hospice's care and who had received an invitation to attend either the BIE or the MMC during the previous 10 months ($n=377$) were invited to take part in the anonymised postal survey. Not all invitees attend BIEs, but we were interested in the views both of attenders and non-attenders.

A bereavement service questionnaire (BIE BSQ) was devised, based on information drawn from other parts of the wider study and other bereavement intervention studies (eg. Parkes, 1981). The questionnaire covered general background information about the participants and questions that sought their views on the BIE. A second BSQ was also developed to obtain views about the MMC (MMC BSQ). A small number of items relating to the BIE were

included in the MMC BSQ because these families were also invited to the BIE, and these responses are also included in the data reported here.

The BSQ BIE also included The Texas Revised Inventory of Grief (TRIG) (Faschingbauer, Zistook & DeVaul, 1987), which provides a measure of grief reaction both at the time of the death and at the time of completion of the questionnaire. The TRIG is easy to complete, in common usage, and ideal for a postal survey (Neimeyer & Hogan, 2002). The internal consistency of the scale is also good (Faschingbauer, Zistook & DeVaul, 1987), enabling a measure of differences between the grief reactions of service attenders and non-attenders.

A subsample of attenders ($n=8$) and non-attenders ($n=14$) was also invited to participate in one-to-one interviews. These semi-structured interviews were recorded, transcribed and subjected to a standard thematic analysis (Addington-Hall *et al*, 2007). The study was approved by the hospice ethics committee.

Results

A total of 192 people were sent the BIE BSQ ($n=192$) and 185 the MMC BSQ, almost half of whom returned completed questionnaires (41% ($n=78$) BIE BSQ; 48% ($n=89$) MMC BSQ; total response 45% ($n=167$). Approximately one quarter of all respondents ($n=43$) reported that they had attended a BIE (112 did not attend, 12 were not sure if they had). For convenience and brevity, the results from both the BIE BSQ and the MMC BSQ and the one-to-one interviews are presented together below.

Perceived helpfulness of the BIE

Approximately three-quarters (76%; $n=127$) of respondents reported that they had received an invitation, and more than one-third of these (34%; $n=43/127$) said they had attended a BIE. Three-quarters ($n=32/43$) of attenders indicated that they were satisfied with the BIE, although they varied as to which aspects they found most helpful. The following information was reported as helpful:

- people grieve differently, even members of the same family
- people may feel ups and downs throughout the grieving process
- it is not unusual to feel the presence of the deceased around you
- the wide and disturbing range of emotions that one can experience
- to know that what they were going through was 'normal'
- the description of the hospice support services and of the grieving process
- the normality of moving 'in and out' of grieving
- to know that they were not alone.

Attenders also said they found it helpful to talk with others at the BIE who had suffered a similar loss.

Reasons for attending the BIE

Respondents gave a number of reasons for attending the BIE. More than one-third ($n=15/43$) were looking for help with coping with their loss; a quarter ($n=11/43$) wanted information on bereavement and the bereavement support services provided by the hospice. One in five specifically wanted to know if what they were going through was ‘normal’. A similar number wanted to meet others who had suffered a similar bereavement. Other reasons for attending included the opportunity to introduce family members to the hospice bereavement services ($n=2/43$), and small numbers felt they either ought to, had to or simply wanted to attend.

The timing of the BIE

Respondents attended the BIE between three and six months after the death. Over half (59%; $n=46/78$) of those answering this question found the timing of the BIE to be appropriate, although approximately a quarter (26%; $n=20/78$) felt it was too soon after the death, and 9% ($n=7/78$) felt that it was too late (10 did not answer this question). Those who attended the BIE were more likely to agree that the timing was appropriate than were those who did not attend (77% and 54%, respectively). Almost a quarter (22%; $n=17/78$) felt that the timing (7pm on a weekday evening) was inconvenient and would have preferred a weekend (9/15), a weekday afternoon (2/15), a weekday early evening (1/15) or a weekday early morning (1/15).

Hospice as a venue for the BIE

Two-thirds ($n=52/78$) of respondents felt it was appropriate to hold the BIE at the hospice. However respondents and interview participants who had relatives who had died at home in the care of the hospice home care team reported that they had a weaker ‘connection’ to the hospice than those whose relative/friend had died in the hospice.

For most, the thought of going back to the hospice evoked sad and often painful feelings. However, some felt either positive or ‘not sure’ about their feelings, and others said they felt ‘good’, ‘overjoyed’, ‘pleased’, or ‘interested’. One woman who had lost her father commented:

‘It was a very strange feeling – sad that my dad was no longer there but happy to see the staff and other bereaved families who we met at the hospice in the four months Dad was there. It’s still very hard driving past the hospice.’

Another woman whose mother had died said:

‘[I] felt a little nervous, but I had spent so much time there, it was like going back to my second home.’

Attendees and non-attendees

Those who attended the BIE scored higher on parts one and two of the TRIG than those who did not attend, suggesting that attendees were more distressed than non-attendees, both at the time of death and at the time they completed the questionnaire. The deceased relatives/friends of attendees were also significantly younger than those of the non-attendees. Attendees were also significantly more likely to be the main carer, to have a closer relationship to the deceased, and to have lower levels of perceived emotional and practical support available to them at the time of the death (see Table 1).

Discussion

The aim of this study was to elicit respondents’ (attendees and non-attendees) views and experiences of the BIE as it has been operating to date. Only one third of respondents accepted the invitation to the BIE, but those requiring more support, as indicated by their scores on the TRIG, were more likely to have attended. For the most part, the majority of respondents were

Table 1: Comparison of BIE attendees and non-attendees on key variables

Variable	Non-attendees		Attendees		p value	t (df)
	n (%)	Mean (sd)	n (%)	Mean (sd)		
TRIG part 1	42	26 (8)	100	22 (8)	.007**	2.74 (140)
TRIG part 2	42	51 (11)	103	45 (12)	.003**	3.05 (143)
Age of deceased	42	62 (17)	106	68 (13)	.016*	2.46 (146)
Main carer	35 (88)	-	68 (67)	-	.04*	6.25 (2)
Emotional support					.002**	20.25 (6)
Practical support					.026*	14.32 (6)

Note: * $<.05$ ** $<.01$

satisfied with the BIE and found various aspects of it helpful. However, there were some adverse comments about the timing of the event and use of the hospice as a venue.

A key question for bereavement service providers is timing: when is it appropriate to offer help? Offering more intensive interventions, such as therapeutic counselling, too early after the death can be detrimental and ineffective because the emotional, social and practical consequences of the loss have not yet followed their natural course (Schut *et al*, 2002). However, the BIE both informs bereaved relatives and friends about the bereavement process and the services available at the hospice, and provides bereaved people with an opportunity to link in with other hospice services, thereby making it easier for those most in need to access more intensive support such as the hospice's volunteer bereavement support service.

A substantial proportion of participants thought that the invitation was sent out too soon. This reflects, perhaps, people's very varied and individual responses to grief, which presents a challenge for service providers seeking to respond in an effective and sensitive way. The hospice has attempted to address this by making provision for bereaved people to change to a later BIE if they wish. However, this system does not cater for the one in ten who found the three to six-month wait was too long. One option would be to send a bereavement information leaflet routinely to all families at the time of the death to inform them about the BIE and inviting them to contact the hospice if they wish to attend it earlier.

Another potentially important factor is the accessibility and suitability of the venue. Although some people clearly found it painful to return to the hospice, most of those who wanted to attend the BIE did so. However, one in eight people who did not attend said that they did not want to return to the hospice. All the hospice bereavement services are offered on site, apart from the follow-up contact by phone call, home visit or letter from a hospice team member two to six weeks after the death, and the annual remembrance service, which is held at the local church. It is important that people who cannot bring themselves to return to the hospice are not left unsupported and that they are made aware of alternative sources of support in the community, such as local counselling services and bereavement support groups.

Many organisations that provide support for the bereaved initiate contact shortly after the loss (Schut *et al*, 2002; Field *et al*, 2004) via, for example, a visit or phone call to a family member from a hospice nurse. Inviting families to attend a BIE is another example of a proactive supportive service strategy. An initial offer of low-level support may be good practice, given current concerns about the reliability of assessment methods and their ability accurately to identify those in need of more intensive support (Payne & Relf, 1994; Relf, Machin & Archer, 2008).

Proactively issuing invitations to low-level support services such as information evenings is also a means to provide information about the availability of more intensive

forms of support for those who need them. The BIE at the hospice appears to function as an important 'gateway' to the hospice's more intensive support services, such as the volunteer bereavement support service (VBSS). For example, almost two-thirds (62%) of those who accessed the VBSS had also attended a BIE. Furthermore, more than one in five (22%) of those who accessed the VBSS first heard about the service at the BIE.

It is interesting to note that BIE attenders tended to be more distressed than those who chose not to attend, both at the time of death and at the time they completed the questionnaire. Reassuringly, this suggests that those who are more distressed, and therefore in more need, are accessing the service. This is further underlined by the fact that those who attended the BIE were also significantly more likely to say they had less emotional and practical support available to them at the time of the death.

However, Cherlin *et al* (2007) found that over half the bereaved caregivers who were identified in their study as having a major depressive disorder did not access any bereavement services, thereby indicating that the most vulnerable may not always seek help. The hospice does not send a bereavement information leaflet routinely to all families, although the leaflets are widely available at hospice events. This leaflet could be sent to all families shortly after the death, followed by an invitation to the BIE to provide the next tier of bereavement support that some families require.

Conclusion

The findings from this study indicate that the BIE is a useful way to inform families about grief and the support services available. More importantly, however, it allows families to meet staff and other bereaved families at the hospice, and also provides a means for people who might need more intensive forms of support to link in with the service, which many may find easier than picking up the phone and asking for help. Thus, the BIE seems to offer an acceptable form of tier two support for those who may need more than an information leaflet but may not necessarily require more intensive one-to-one support.

The proactive provision of accessible low-level support (eg. tier one written information) and the second-tier support provided by the BIE, with its ready link to more intensive support, may constitute an appropriate strategy for in-hospice bereavement services, both in Ireland and elsewhere. However, the findings of this study suggest that measures might also need to be put in place to ensure that those who are unable or unwilling to attend these kinds of events also receive sufficient information about the bereavement process, further support events, and the higher-level support services available. ■

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