Qualitative evaluation of a hospital bereavement service: the perspective of grieving adults

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Abstract: Bereavement and grief are natural processes and the majority of people find their way through their loss. However, a small minority may benefit from professional assistance and a service that meets their needs. The aim of this study was to evaluate the impact of an Australian Hospital Bereavement Service on the next of kin of deceased patients. The service provides three consecutive tiers of support to palliative care patients and families including information and compassion, non-specialised bereavement support and specialist intervention referral to external agencies on an individual and selective basis. The research used a qualitative approach with semi-structured focus groups and thematic analysis. Major themes identified were personal experience of grief; revisiting the hospital; and bereavement care experiences. We conclude assumptions should not be made about bereavement needs or grieving reactions of individuals. However, a suite of appropriate bereavement services, support groups and feedback opportunities are perceived as helpful by grieving adults. The research also highlighted how difficult it is for some family members to return to the hospital following the death of their loved one.

Keywords: hospital services, adults; support groups; service feedback; tiers of support; revisiting

Introduction

The bereavement literature frequently refers to the challenges and difficulties in researching both bereavement care and the effectiveness of certain interventions (Schut & Stroebe, 2011) yet provides little guidance for treatment interventions (Forte *et al*, 2004). This dearth of information extends to the primary health care and community settings where there are also only a small number of studies, most of which do not reflect contemporary practice (Nagraj & Barclay, 2011). The exception is in the specialised area of bereavement assessment tools (Renzenbrink, 2002).

St John of God Subiaco Hospital is located in a capital city in Australia. It is a 621 bed faith-based private hospital, which includes a comprehensive cancer centre with five palliative care rooms. The multidisciplinary palliative care service is provided by the Palliative Care Physician, Palliative Care Nurse Practitioner, Pharmacist, Social Worker, Physiotherapist, Occupational Therapist and Pastoral Practitioners. The study hospital Bereavement Service was set up in July 2010 following a process of consultation and development across the hospital led by the Manager of Pastoral Services, the Palliative CNC and the Director of Inpatient Services. Subsequently, a discussion paper on the development of a hospital wide bereavement framework and policy was released.

A bereavement support policy was developed and based on this, the service includes:

- An updated Bereavement Pack of information provided where appropriate, to the family of every dying patient;

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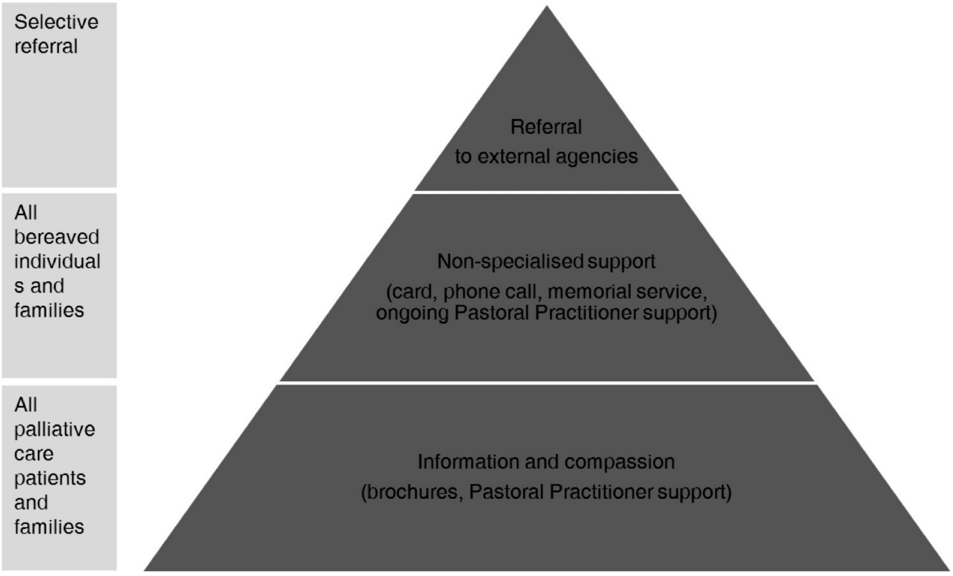
Figure 1: The study hospital's approach to bereavement support



- An informal review of each death by the multidisciplinary palliative team and informal identification of family members at risk of complex bereavement;
- A card sent within one week of death to the next of kin of every patient who died in the hospital;
- A follow up phone call made to the next of kin approximately six weeks after the death;
- The offer of one session in Pastoral Services or referral to a community agency if required by the next of kin;
- Invitation of next of kin to a Memorial Service in the hospital chapel within six months of the death; and
- The patient's name added to the Hospital Chapel Memorial Book.

The aims of the research were:

- To evaluate the impact of the study hospital's Bereavement Service on the next of kin of deceased patients;
- To identify which strategies used in the Bereavement Service are experienced as most helpful and supportive by bereaved people;
- To identify any additional strategies that next of kin may require from the service to support them.

Background

In reviewing the available studies, the model known as 'the public health approach to bereavement' does offer a useful framework within which to view a Bereavement Service such as that offered by the study Hospital (Aoun *et al*, 2012). The authors describe a 'three-tiered model of bereavement care' which includes three types of support depending on the needs of families:

1. Information and compassion;
2. Non-specialised support; and
3. Specialist intervention (Aoun *et al*, 2012).

The study hospital Bereavement Service can be conceptualised along a similar framework. The focus of the Bereavement Service is on providing two consecutive tiers of support:

1. Offering information and compassion to palliative care patients and families; and
2. Non-specialised bereavement support to individuals and families.

However, it is evident that the study hospital Bereavement Service is capable of meeting the needs of bereaved people at a third level through specialist intervention referral to external agencies, on an individual and selective basis. Figure 1 provides a model of the bereavement support services provided at the study hospital.

This model is similar to the 'stepped approach' recommended in the UK NICE Guidelines. This approach includes practical and emotional support, information and referral to more specialist support (National Institute for Health and Care Excellence (NICE), 2011 p2).

The literature indicates that a variety of interventions have been and are used in bereavement care. A prospective, randomised, controlled trial by Lautrette and colleagues reported the effects of offering a brochure and an extended end of life family conference, concluding that providing relatives with a service that includes these interventions may lessen the burden of bereavement and have a positive effect on their experience (Lautrette *et al*, 2007).

Given the growing use of the internet as a source of everyday information it is reasonable to expect that bereaved people may search the worldwide web for support. Likewise, organisations are increasingly investigating ways to utilise the medium to support bereaved people, with one study in particular reporting the positive potential of the internet to assist bereaved people in normalising their grief and enhancing their adaptive adjustment (Dominick *et al*, 2009).

There is also some research on the efficacy of bereavement support groups of various kinds. The authors of an article on the coping of bereaved spouses/partners following their involvement in an intervention based on what was called 'a dual process model' (Lund *et al*, 2010; Stroebe & Schut, 1999) concluded that nearly all measures of motivation and satisfaction were highly favourable, with participants reporting they had their needs met and they were able to apply learned strategies to their daily lives. Similarly, a study of widowers in a group program found that there was a decreased physician visit rate amongst those taking part in a mutual support program suggesting that the program met some of the widower's social support needs that would have otherwise led to the use of health care resources (Tudiver *et al*, 1995).

As illustrated, bereavement services in healthcare settings are as varied as the people they serve and the people who provide them. Given the vulnerability of bereaved people, it is important that services/support provided are based on sound foundations and best practice. Bereavement and grief are natural processes and the majority of people find their way through their loss, however, a small minority may benefit from professional assistance and may need information on how to access such support. Bereavement Services as provided by a hospital offer the opportunity to complete the cycle of care which begins at the time of admission. It is important that the service being offered best meets the needs of those receiving it.

Methods

Research design

This research was conducted using a qualitative design to allow for description of the experience rather than in-depth interpretation (Polit & Beck, 2010). The approach was to use semi-structured focus groups followed by thematic analysis of the material gathered in the focus groups.

There were three main focus questions in relation to the main interventions of the Bereavement Service, outlined at the beginning of each focus group:

1. What helped?
2. What was unhelpful?
3. What else would have helped you?

Setting and sample

The recruitment strategy for the study was to send out invitations, in the form of a letter to the next of kin of all those adult patients who died in the hospital in 2012, inviting them to participate in the research. This cohort was chosen because the death of their loved one was at least almost 12 months in the past, without being so far in the past that they might not see such a project as relevant to them. It was hoped that focus groups would be organised around the participant's relationship with the deceased, with sufficient numbers for up to five groups with up to five participants in each. The research proposal suggested that these would include the following groups:

1. Female partners of the deceased;
2. Male partners of the deceased;
3. Parents of the deceased;
4. Sons/daughters of the deceased (over 18 years);
5. Siblings of the deceased (over 18 years).

A total of n=236 family members were invited to participate in the study. The response rate to the invitation to participate was less than anticipated with data for this study collected from a total of n=17 participants (n=14 female and n=3 male). The majority of participants were partners (husbands or wives) of the deceased (n=14). The remaining participants (n=3) were adult daughters of the deceased. Focus groups were not organised around the participant's relationship with the deceased, rather they were organised around participant's availability. Four focus groups were held over a period of eight days. Focus group one comprised five female participants, focus group two comprised three female and one male participant, focus group three comprised three female and two male participants and focus group four comprised three female participants. The focus groups were held in the Pastoral Services Department seminar room of the study hospital.

Inclusion criteria and exclusion criteria

Participants younger than 18 years of age or non-English speaking people were excluded from the study. Participants with diagnosed depression (where this was known) were excluded from the study. This was a requirement of the Human Research Ethics Committee, as was the inclusion of a distress protocol in the event that any participant required professional support as a consequence of their involvement in the focus group.

Ethical considerations

An application to undertake this research was submitted to the study hospital's Human Research Ethics Committee (HREC). The application sought approval to conduct focus groups with next of kin of deceased patients from the study hospital. An application was also submitted to the affiliated university for approval under minimizing duplication protocols. Ethics approval to conduct the study was granted contingent on the criteria specific to managing research with vulnerable participants.

Data collection

To capture the participants' experience of bereavement an open ended interview technique was used in the focus groups. This allowed the participants to express their experiences without being led by the researcher (Minichiello *et al*, 2008). Prior to commencing the focus groups, the potential participants were fully informed about the research and an information sheet was given to them explaining the research and the nature of their participation. In order to minimise the possibility of researcher bias in the study, an independent, experienced facilitator conducted the focus groups. The facilitator was not acting in a professional role, although she is a Registered Nurse and was therefore able to manage any initial distress should it have arisen. The facilitator utilised a planned approach to the group process that included time to build and establish rapport, guiding the discussion while allowing participants an opportunity to contribute and give rich, accurate accounts of their experiences, and applying the techniques of questioning, probing and cross checking (Minichiello *et al*, 2008).

All group discussions were digitally recorded, while the facilitator listened attentively and analytically, and field notes were made at the time. The researcher transcribed the discussions verbatim. All transcriptions were reviewed by the focus group facilitator to ensure that the meaning of the participants' accounts was reflected in the transcript. In attempting to minimise the possibility of transcription error, cross reference to field notes occurred during the transcription process (Poland, 2001).

Of interest to the process of conducting the focus groups, in the case of two participants some distress was expressed during the discussion. This was initially managed by the focus group facilitator. The respective participants were then referred to Pastoral Services for a one off consultation with a pastoral practitioner or a community agency if preferred. Additionally, following the focus groups, some of the participants remained in discussion, talking and sharing their respective experiences with one another. This interaction was supported and encouraged, with participants invited to stay in the meeting space for as long as they needed.

Data analysis

Transcribed group discussions were analysed using thematic analysis (Vaismoradi *et al*, 2013; Loffe & Yardley, 2003; Braun & Clarke, 2006). Both researchers independently read and reread the interview transcripts and familiarisation with, and immersion in the data in this way exposed patterns, ideas and threads from key words, phrases or sentences. Independent preliminary coding was undertaken with the words, phrases and other interesting elements of the transcribed interviews organised into groups with similar meanings, as understood by the researchers (Braun & Clarke, 2006). Importantly, the coding process deliberately ensured that coded extracts from the transcriptions remained in context thereby staying true to the raw data (Loffe & Yardley, 2003). Analysis occurred after all the data was collected in preference to concurrent data collection and analysis. The analysis was done manually as described in Taylor (2007), and Braun & Clarke (2006) until a final collection of themes emerged.

The development and subsequent inclusion of a theme was not contingent on the frequency of a word, phrase or even a theme itself (Morgan, 1993). Rather, a theme was considered relevant to the research because it captured an element that was deemed to be important to the overall research into the experience of the Bereavement Service and was consistently described by participants within and across focus groups. Thematic analysis methods identify, analyse, and describe emerging patterns that ultimately develop into themes (Braun & Clarke, 2006). The detailed analysis explored and revealed the meaning of the participants' interviews, rather than simply undertaking a superficial consideration of the transcript (Bloor & Wood, 2006).

In analysing the interviews, significant engagement with the transcripts occurred. The process of transcription, reading, coding and theme derivation was substantial, resulting in a deep understanding of the experiences of bereaved adults. This commitment to the understanding and analysis provides a basic level of quality (Marks & Yardley, 2003). Further, the thematic analysis followed a systematic approach as advocated by, and similar to the method of Braun and Clarke (2006). The following presentation and description of the emergent themes, with supporting excerpts, provides the best opportunity to demonstrate the rigour of the data analysis through the development of new insights into the experience of bereavement services by adults (Rolfe, 2006).

Results

Personal experience of grief

In each of the focus groups the participants spoke about the very personal and difficult nature of grief and their varied experiences and needs in their grief.

> *'I know people are different in grieving and I will never stop grieving…each individual person is different.'(Focus Group 3/Participant 2)*

There was recognition that what was helpful to one may not have been helpful to another eg regarding the Memorial Service.

> *'I guess it's each individual thing…you know you need help but you don't know what it is you need.'(FG3/P1)*

Revisiting the hospital

There were two quite divergent views expressed regarding revisiting the hospital following the death of a loved one. For some of the participants in the study, the hospital is a significant place for their family and returning to this hospital provides a source of comfort. They described returning to the hospital to attend the Memorial Service, their own medical appointments or to visit patients.

> *'For me there's a sense of comfort here. I worked here, I was born here, my husband was born here, he died here and the whole process of him going through cancer ... I just felt comfortable'. (FG2/P2)*

However, for other participants in each of the focus groups, returning to the hospital for any reason following the death of their loved one was very difficult.

> *'I wouldn't come back for anything I felt I didn't need to. No, I wanted to stay right away. I mean I only live three minutes away. I frequently drive past and each time I don't like it. Then last week I came to the dermatologist. It was awful'. (FG1/P2)*

The attendance of participants at the focus groups is testament to their appreciation of the hospital's Bereavement Service.

> *'I thought it was important. In this way you can give something back to the hospital.' (FG1/P2)*

Bereavement care experiences

Participants saw integration of the pastoral staff in the clinical team as important.

> *'The thing I really liked was that obviously everyone talked to each other, so the medical staff and the pastoral staff obviously integrated.'(FG1/P1)*

Aside from the dedicated bereavement services, participants reported overall that the hospital staff were almost without exception caring, personal and professional around the time of death of their loved one and during their bereavement.

> *'Every single step of the way, the support from the hospital, the nursing staff, you could not fault it in any way. The kindness and the way they treated us after he died in the hospital was just second to none. I could not praise them enough. They were just so kind and gentle with us'. (FG3/P4)*

Participants reported that the most important elements of the care provided were practical information, the opportunity to stay overnight with their loved one and the staff support generally.

> *'I only had six weeks, less than that in hospital. And if I hadn't had been able to sleep there with her I would have been shattered. But what it means for the hospital, if you want to know what services they provide, to me that was the most critical thing they provided'. (FG3/P1)*

> *'She had very practical advice. She said get yourself a notebook to carry in your bag because there are so many things you are going to have to do and you won't be able to remember it … She was very very good with lots of practical things like that that made such a difference'. (FG1/P1)*

Finally, the participants reported that they specifically appreciated that the support for bereaved people was non-religious despite the fact that the hospital is a faith-based hospital and the service is provided from the Pastoral Services Department.

> *'I thought any pastoral care and anyone you spoke to was going to spruik [tout] religion to you. But once I started to talking to them I realised they weren't trying to do that and I think maybe if there was a way that that could be communicated, if I had known that, I might have chatted to someone a little bit earlier'. (FG2/P3)*

Participants in this study identified the importance of various aspects of the bereavement care as it is currently provided. The existing sympathy card, phone call and memorial service invitation were consistently praised for their value.

> *'None of those upset me at all, and I found comfort in all of them and it was nice to have the follow up'. (FG1/P4).*

As indicated in the theme 'Revisiting', some participants felt unable to return to the hospital for the Memorial Service either because the service was held in the same hospital as their loved one died in or because the service was too close to the time of death.

> *'It's too close, it's too raw'. (FG3/P2)*

This was the only reference made by participants to the timing of the interventions offered.

Discussion

Bereavement is a life event that most people will experience and in most cases it is not a pathological or medical condition requiring professional intervention (Nagraj & Barclay, 2011). Nonetheless there are individuals and families who seek specific support during the period of palliative care and bereavement according to the nature of their experience. The study hospital Bereavement Service provides a valuable service that complements other support structures that grieving individuals and families have in place.

Participants in the study reported that the information provided in the brochure and compassion offered by the Pastoral Practitioners were both highly valued and contributed positively to the pre and post-bereavement periods. The non-specialised interventions offered by Pastoral Practitioners and other hospital staff are appropriate and significant universal interventions. Additionally the interventions of the card, phone call and memorial service were perceived as helpful interventions by most participants.

In addition to the current interventions and support offered across the three levels, there was evidence to suggest that further support could be offered to bereaved people. Participants spoke about the value of sharing with one another about their loss and continued talking with one another beyond the scheduled focus group time, suggesting that it may be important to explore an opportunity to offer a bereavement support group or referral to other organisations offering such groups. Similarly, as a number of the participants spoke about the difficulties of revisiting the hospital following the death of their loved one, further support could be offered to assist with revisiting either through the Pastoral Services Department or through another service within the hospital. Finally, participant's interest in providing feedback to the hospital on their experiences at the time of death of their loved one suggests something be put in place beyond the ordinary feedback mechanisms to enable this to occur.

Study limitations

The findings of the study illustrate that revisiting the hospital can be difficult for bereaved family members. For this reason the participants in the study do not represent all people who have experienced bereavement at the study hospital. Future research using a qualitative approach into bereavement care should consider holding some interviews at a site alternate to the hospital in which the patient died.

The participant group did not include bereaved parents or bereaved children less than 18 years of age, therefore it is not possible to generalise the recommendations to these groups. A sample with greater diversity in age and relationship to the deceased may elicit additional themes.

Finally this study was confined to the study hospital and as such the findings reflect particular practices and therefore may not represent the practices of other hospitals.

Implications for clinical practice and future research

On the basis of the findings of this research, it is recommended that a suite of appropriate bereavement services be offered to grieving adults in other hospitals, which replicate those of the study hospital. These include a personalised card sent to bereaved people, a follow up phone call, and informative and practical brochures. Additionally, support groups for bereaved people may provide an opportunity to interact with other individuals experiencing grief and loss, particularly if the focus group is held at the hospital where some participants found a feeling of comfort due to familiarity with the place and with the health professionals. Exploration of ways in which support could be offered to bereaved people experiencing difficulties revisiting the hospital should be explored, given that there may be a time in the future where they may need to return to the hospital. Finally, services should explore opportunities for bereaved relatives to provide feedback on their experiences to the hospital.

This research explored a sensitive topic with a vulnerable population and as such, undertaking the study was not without challenges. Proposing, undertaking and reporting on the study required consideration of issues such as distress protocols for participants, creating a supportive environment to discuss a distressing topic, managing the fine line between a research focus group and a support group, appreciating the role of the researcher as the group facilitator, and understanding the 'data' and its credibility (Briller *et al*, 2007; Kitzinger, 1994; Owen, 2001; Seymour *et al*, 2002). Recognising, managing and overcoming these significant ethical, practical and methodological challenges ensured that rich and meaningful data on an inherently difficult topic has been gathered sensitively and reported accurately.
In addition to reporting on the Bereavement Service, this report evidences the importance of understanding and considering research design and planning when investigating sensitive issues from the perspective of vulnerable participants. Barriers that arise in planning and executing focus groups in difficult research settings should not preclude such research from occurring.

Conclusion

This small, descriptive, qualitative study has established that the Bereavement Service at the study hospital, with the range of interventions offered, is experienced as useful and helpful by the bereaved families of patients. No particular strategy was identified as more helpful than the others and minor adjustments to the service would be worthwhile.

With regard to the Bereavement Service offered, two additional strategies were identified that may be helpful to bereaved people. The interest of participants in talking to one another and sharing their experiences suggested that referral to a support group could be very helpful. Further, in undertaking the research it was clear that bereaved relatives seek an avenue to provide information back to the hospital about their individual experiences.

The study highlights that bereaved individuals and families experience grief in a unique way. For the families of dying patients, the care that they receive from hospital staff both prior to and after death is perceived as very important and may contribute to their individual healing as they move through their grief. This research also highlights how difficult it is for some family members to return to the hospital following the death of their loved one and that because grief is always a personal experience, assumptions should not be made about individual's needs and reactions.

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