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'Through the eyes of the dying' - Identifying who may benefit from bereavement follow-up: A qualitative study

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Title 'Through the eyes of the dying' - Identifying who may benefit from bereavement follow-up: a qualitative study

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Key statements:

Problem or Issue

Routine bereavement follow-up ought to be reserved for those most in need of support. However, most specialist palliative care services provide bereavement support to the decedent's nominated next-of-kin. Yet, there may be other people within the dying patient's kinship and social networks who are also in need of bereavement support.

What is already known

- Supporting people through loss and grief is an integral element of palliative care provision;
- In specialist palliative care services most initial bereavement follow-up is provided by nurses; and

- Accessing bereavement counselling services requires those in need of such services to acknowledge that they require them, and this may not always be possible for a person who is grieving.

What this paper adds

- There is a potential discordance between who is routinely offered bereavement support and whom the patient perceives will need bereavement support following their death.
- Supporting nurses to ask those living with advanced disease to identify those who may need support after their death will enable bereavement follow-up to be more efficaciously targeted, and it may not necessarily be the patient's nominated next-of-kin; and
- There is a need for bereavement assessment forms be developed to guide conversations for assessment rather than advocating for a specific tool to identify bereavement risk.

Introduction

Grief is a response to a significant loss that is often a very stressful experience. Fortunately, most people have sufficient internal and external resources to cope with their loss, readjust to life without the deceased and will not need psychotherapeutic intervention (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor, 2017; Neimeyer, Harris, Winokuer, & Thornton 2011). Supporting people through loss and grief is an essential component of care for people approaching and reaching the end of their lives, their families and carers, and is an integral element of all palliative care (Palliative Care Australia, 2018a). To deliver the highest standard of care there is a requirement to ensure that the patient, their caregiver/s and family have access to bereavement information and support services (Palliative Care Australia, 2018b).

In Australia, most palliative care services provide anticipatory grief and bereavement support to the patient's nominated next-of-kin (Phillips, Lobb, Piza, Austin, Mohacsi, & Currow 2018). Such support may be provided by a nurse, a social worker, a pastoral care worker or a clinical psychologist and can commence when the patient is referred to the community or in-patient palliative care service and continue after the patient's death.

Bereavement support practices after the patient's death may vary between palliative care services and can consist of nursing, pastoral care or social work support immediately after the death followed by a letter of condolence, a brochure or a booklet on the "grieving process" and contact details for a bereavement counselling service. Some palliative care services send a card on the anniversary and hold annual memorial services. The address of the next-of-kin indicated on the patient medical records identifies to whom and where to mail this information.

Outside of this approach accessing additional support relies on the bereaved individual contacting the bereavement counselling service (Parkes, 1996). This form of intervention relies on the bereaved to make a rational, objective decision which may be difficult at the time when they are most in need (Parkes, 1996). Consequently, individuals who may not be coping well may delay finding help or may become more distressed which can result in an under-recognition of those most in need of receiving support. Despite the advances in bereavement evidence, identifying those most in need of bereavement support continues to be an inexact science. Bereavement interventions for people with normal grief, where people tend to experience strong emotions, a sense of cognitive disequilibrium and impaired role function for a short period of time and improve without formalized help, (Currier JM, Neimeyer RA, & Berman JS, 2008) have been found to be largely ineffective and

unnecessary (Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012; Prigerson & Jacobs 2001). Indeed unnecessary interventions may disrupt the natural course of grieving and result in a loss of social-support if friends and family withdraw from the bereaved as a result of their receipt of professional services. (Aoun, Breen, Howting, Rumbold, McNamara, & Hegney, 2015).

While most people who experience grief do not require specialist counselling, most will benefit from reassurance and acknowledgement of their losses, and access to information. A 2008 palliative care survey of bereaved family members found almost half expressed a need for bereavement support, and most preferred that this follow-up be conducted at their home and preferably by a member of the team most involved in providing care (Milberg, Olsson, Jacobsson, Olsson, & Friedrichsen, 2008).⁹ A more recent Australian qualitative study found that bereavement support offered by specialist palliative care services is often not widely used by family carers, many of whom are next-of-kin. Participants reported that they saw bereavement as personal, that they were “strong willed” or “emotionally stronger than others” and their preference was for practical assistance with the logistical tasks following the death of a relative rather than psychotherapeutic interventions. (Kirby, Kenny, Broom, MacArtney, & Good, 2008. p.402). Despite, this evidence most specialist palliative care services continue to provide routine bereavement follow-up to the decedents nominated next-of-kin (Phillips, Lobb, Piza, Austin, Mohacsi, & Currow, 2018; Aoun, Breen, Howting, Rumbold, McNamara, & Hegney. 2015). While previous research has examined the perspectives of family carers (Milberg, Olsson, Jacobsson, Olsson, & Friedrichsen. 2008; Kirby, Kenny, Broom, MacArtney, & Good, 2008).^{9, 10} and who receives bereavement follow-up (Phillips, Lobb, Piza, Austin, Mohacsi, & Currow 2018), no previous research has examined whom people with palliative care needs consider are most in need of bereavement

support. Obtaining this perspective from palliative patients may help to improve the efficacy and target of future bereavement interventions (Lichtenthal, 2018).

Refocussing bereavement support on those who most need it and moving it beyond the nominated next-of-kin is particularly important given the diversity and complexity of modern families and kinship networks. For example in Australia: 14% of families are now one parent families; 8.3% of households contained extended family members; and 2% are classified as ‘other family’ that consists of neither couple relationships nor parent-child relationships (Relationships Australia, 2018)

Aims

To explore the degree to which people with palliative care needs and are inpatients are concerned about the bereavement needs of people other than their nominated next-of-kin; and
To assess the feasibility of specialist palliative care nurses asking these questions.

Methods

Study design: A qualitative study using semi-structured interviews.

Setting and sampling: A purposive sample of eligible in-patients from a specialist palliative care unit, in Sydney NSW Australia were approached to participate in a one-off semi-structured interview. To be eligible for inclusion, patients needed to be aware of their limited prognosis, deemed well enough by their physician to participate in these conversations, speak English and be comfortable communicating the expectations and concerns for people within their family or kinship networks who they considered may be in need of bereavement support following their death.

Recruitment approach: All participants were identified by their treating physician as being

aware of the life-limiting nature of their illness and prognosis, with this information documented in their current admission notes. Eligible participants who expressed a willingness to participate in the semi-structured interviews were approached in person by the interviewer (FB). They were provided with verbal and written study information, explaining that the interviews would explore the potential bereavement needs of people within their networks.

Data collection and analysis: Given the sensitivity of the conversations, a semi-structured interview format was considered the most appropriate way of seeking the perspectives of participants, and also a way of providing them with an opportunity to talk about any concerns they may have about their death and/or about the people that they were leaving behind. The interview process was refined after being piloted with nine patients (June-December 2013), to focus the conversation on identifying the person(s) that participants' were most concerned about and thought might be in need of bereavement support. (Refer Textbox 1). The interview questions themselves were not altered but rather structured in a way to support the patient, who, at times, could lose their focus. An experienced, female specialist palliative care clinical trials nurse (FB) established rapport with the participants before conducting the interviews, which were digitally recorded and professionally transcribed with participants' permission. The pilot interviews were all conducted in a place and time of the participants choosing with just the researcher present. However, time and funding constraints limited subsequent interviews (February 2016-17) to the in-patient setting. Demographic information relating to participants' ages, genders and diagnoses was obtained at the end of the interview. All data was managed in an excel spreadsheet.

Detailed field notes taken during the research process added rigor to the research process. Data were collected until no new themes were generated. Data collection and analysis was undertaken concurrently as reflexive activities. The interviewer (FB) reflected on their bias and assumptions and kept detailed field notes. Thematic analysis (Braun & Clarke, 2006) was

undertaken using a constant comparative method, with themes determined inductively. Repeated engagement with the audio, transcription files and field notes (FB, JLP and TH) allowed for immersion in the data, and consideration of how things were said and the various points of emphasis. Preliminary note-taking preceded the formal development of 'code', generated by a third researcher (TH) using the interview questions as a guide. Three team members (TH, FB and JLP) discussed the emerging themes, selected typical quotes and preserved their context (Braun & Clarke, 2006). Participants were offered the opportunity to review their transcripts for comments and/or corrections.

Ethics: The research team sought the input from an interdisciplinary 'new studies working group' which assisted in identifying and addressing potential ethical issues prior to study commencement. This approach also ensured that all of the necessary strategies were in place to manage any issues that may have arisen. Human Research Ethical Committee (HREC) approval was granted in 2013 for 5 years (HREC Number LNR/13/SVH1) with a protocol amendment granted in 2016 following the pilot phase to relocate the interviews from the community to the in-patient service. Annual reports were submitted to the Ethics Committee to advise the study was continuing.

Adherence to the *Consolidated criteria for reporting qualitative research (COREQ)* (Tong, Sainsbury & Craig, 2006) has ensured attention to: clarification and justification; procedural rigor; representativeness; interpretive rigor; reflexivity and evaluation rigor; and transferability.

[Insert text box 1]

Findings

Of the 54 eligible palliative care in-patients screened, 19 participated in a face-to-face semi-structured interview [piloting phase (n=9), and phase II (n=11)], representing a 37% recruitment rate over the 20-month recruitment period. Over half of the participants were female (n=11) and the mean age was 71 years. The majority (73%) had a cancer diagnosis. The mean length of the interviews was 33 minutes (9 to 79 minutes). The mean time from the interview until death was 132 days (range 17-483 days), with one participant still alive at the time of study closure (February 2017).

For the majority of participants (68%, n=13/19) the person named as their next-of-kin in their medical records was not the same as the person they nominated during their interviews as being the person that they were most concerned about following their death (Table 2). The people that participants were concerned about included: siblings; their adult children; friends and their parents.

[Insert Table 2]

Three high level themes emerged from the data analysis, namely: 1) Families that were considered close and supportive may not always require bereavement follow-up; 2) Families who have had other significant losses are perceived as needing bereavement support; and 3) While initiating conversations with palliative care patients about whom they are most concerned about in bereavement was difficult, it was also quite feasible with most participants valuing the opportunity to share this information.

1) Close and supportive family members may not always require bereavement follow-up

Participants acknowledged that it was difficult to ‘....*imagine life without one’s partner* as one person reflected on how his partner may be feeling about his impending death.

(Participant 4, male, aged 72). For many participants being part of a cohesive family unit

made it easier to think about the future, especially knowing that their nominated next-of-kin (spouse/partner) would be adequately supported by other family members.

...wife most affected...combined family support should help all concerned...family (siblings) working together as a team of support... (Participant 3, male aged 80).

While the perception that the nominated next-of-kin would not require bereavement support was quite strong, some of the more gendered responses called into question whether these perceptions were accurate or reflected wider gendered stereotypes, as highlighted in this quote:.

...I have no real problems with what they're going to do after I'm gone because I'm sure they'll cope... The men being like most laconic Australian men. But that doesn't mean they are not feeling it (Participant 15, Female Aged 88).

2) Family members who have experienced other significant losses or lived more complex lives were perceived as needing bereavement support

Many participants identified a person other than their nominated next-of-kin as needing additional bereavement support following their death, including an older parent, a sibling or an adult child. The reasons cited were related primarily related to clearly defined extenuating life circumstances, including: being the remaining sibling; having endured other significant losses; having complex life circumstances; and/or living with a long-term physical or mental health disability or communication issues.

...(son) he's the sort of person who finds it very difficult to talk about how he feels and he internalises a lot and feels things very deeply... 'He has the support of family but won't seek support' (Participant 10, Female aged 63).

Having their own family and/or support systems did not always detract from the participant's perception that their parent, sibling or adult children may potentially need some bereavement

support and/or follow-up, especially if they have experienced other losses. A smaller proportion of participant's nominated people other than first degree relatives, such as a grandchild, niece or friend.

...I'm concerned about my Mum as she has already lost a daughter to cancer.

(Participant 9, female aged 65);

...she will take it hard being the last sibling left even though she has her own family

(Participant 1, male aged 72);

Concern(ed) for daughter because my wife died of breast cancer... Who will provide emotional help and support in her time of need?

(Participant 5, Male, aged 88); and

'... because it was just her (twin sister) and I, she felt she could be with me and hold my hand and just let it rip about how she's not coping'

(Participant 16, male aged 53).

Participants also expressed concern for family members who had ongoing physical or mental health illnesses and how their bereavement and subsequent wellbeing may be affected:

... my son has schizophrenia, is adopted ... when people find out about his condition they just wipe him...He lives interstate...I worry about him because we have a wonderful bond and he's angry...It's not something he would do (initiate bereavement support/counselling) himself – he would try to struggle through but his heart would need looking after

(Participant 6, Female, Aged 64 years); and

My grandson with ADHD needs bereavement help... My son who has a young family and only works part-time and is struggling'

(Participant 12, Female, Aged 57);

There was a perception that taking on a significant unpaid carer role, outside of being the next-of-kin may place a family member at risk of needing bereavement follow up:

...my sister will take it hard as she has really taken this on-board and stepped up to care for me

(Participant 10, Female Aged 63).

Similarly, if a family member was not accepting of the participant's death, it was thought that these people would have a poorer bereavement outcome.

...My mother who is 87yrs is not accepting the fact that I am dying

(Participant 12, Female, aged 57).

Other participants were more concerned about the bereavement needs of their adult children than their spouse, primarily because they perceived that they were just starting out in their own lives in terms of relationships, family and career, and hoped that their death would not impact adversely in achieving their dreams:

My concern is my children's future as this has happened at a time when they have just become qualified and started work

(Participant 7, male aged 75).

One participant alluded to another '*...person who could not be named...some things might have to go to the grave with me*' (Participant 3, male aged 80), as potentially needing support. However, because of the need for secrecy, this person would never be provided with bereavement support from the palliative care service.

3) Asking palliative care patients who they are most concerned about after their death is difficult but possible.

Overall, the participants were all able to answer the questions posed to them and were clearly comfortable considering whom within their networks may require bereavement support.

...I think it's a good idea to challenge people who've had a bad diagnosis – challenge them to think about the future instead of putting it under the carpet... (Participant 19, Female Aged 67); and

'Their lives have been formed around mine in many ways, and consequently if I was to suddenly come out of that area, suddenly taken away from it, I just want to know how they could cope with that missing link. One link goes out, you know, I'm sure you've felt that yourself sometimes when you lose anybody, may not be too close to you, might be very close to you, there's an emptiness that goes with it

(Participant 3, Male, 80 years).

While, some of the interviews were long, with the interviewer needing to focus the participants on the topic of the interview most responded directly to the questions and many welcomed the opportunity to reflect and speak about their concerns for others after their death. It was evident that very few had raised these concerns with their next-of-kin, and did not elaborate, while other participants took the opportunity to reflect more broadly on their life and their relationships.

Discussion

This study is one of the first to explore whom people with palliative care needs are most concerned about following their death. The majority of people involved in this qualitative study named someone other than their documented next-of-kin, including: their adult children, their siblings and/or friends; revealing a potential discordance between who is the named next-of-kin and the person that will be routinely offered bereavement follow-up by palliative care services, and the person(s) the patient is most concerned about following their

death. They were all confident in naming people other than next-of-kin as potentially requiring bereavement follow-up primarily because of their nominee's: complex current or previous relationships, social isolation; other significant losses or recent losses; and/or previous history of mental illness or drug and alcohol misuse. In doing so, it is likely that the patients were drawing upon their knowledge of the other person's pre-existing coping mechanisms and perspectives and how they might operationalise these in the face of the patient's death being an added stress (Folkman, 2001).

The factors that led these terminally ill people to nominate the people they were most concerned about after their death are not dissimilar to the predictors that are known to contribute to Prolonged Grief Disorder, including: a lack of family cohesion and a problematic relationship with the deceased; a negative view of self and the world; and previous history of depression or avoidance of emotional problems (Lobb, Kristjanson, Aoun, Monterosso, & Halkett, 2010; Simon, 2013). Many of the people these patients with palliative care needs were concerned about were older people, either an older parent, sibling or friend, who would not normally be followed up or contacted by palliative care bereavement services. This is noteworthy, as significant loss at an older age is associated with poorer health outcomes; higher levels of health services utilisation and higher mortality, which are all factors known to increase the risk of Prolonged Grief Disorder (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor. 2017).

Patients in this study who perceived that their families were cohesive and supportive were confident that their nominated next of kin, either their spouse and/or adult children, were considered unlikely to need bereavement support. Yet, the way our current palliative care bereavement services are configured, these nominated next of kin are the very people that would be followed-up. It has long been suggested that routine bereavement follow-up may not be needed or helpful, and that it ought to be reserved for those most in need of support

(Aoun, Rumbold, Howting, Bolleter, & Breen, 2017). However, it is recommended that specialist palliative care services, at a minimum, provide the patient's families and friends with information about bereavement and relevant supports by health professionals, and that contact with these services be left up to the bereaved individual (National Institute for Health Clinical Excellence, 2016).

A recent meta-analysis found one in ten bereaved adults are at risk of Prolonged Grief Disorder which impacts adversely on their familial, social, and occupational functioning (Lundorff, Holmgren, Zachariae, Farver-Vestergaard, & O'Connor. 2017). This estimate is in keeping with this study that identified a small number of people who, according to the patient, may be considered at risk of Prolonged Grief Disorder. Lobb, Kristjanson, Aoun, Monterosso, & Halkett 2010; Simon, 2013).

Most bereavement guidelines recommend that palliative care services have mechanisms in place to identify people who are at risk of or who are experiencing a complex response to bereavement and to facilitate access to loss, grief and bereavement support experts (Palliative Care Australia, 2018a). The use of bereavement assessment forms may help to guide these conversations so that consideration is given to the nature of the illness, care and death, the characteristics of the bereaved, the interpersonal relationships and the family functioning (Aranda & Milne, 2000).

The findings from this study suggest that there is immense value in nurses providing the patient with the opportunity to be involved in this assessment to identify others who would benefit from being sent information about available bereavement support services. Whilst these conversations were not easy to initiate, the vast majority of the patients welcomed the opportunity to reflect on the people involved in their lives who may benefit from some sort of bereavement follow-up. These conversations are also likely to be easier to initiate by an experienced nurse who has an established relationship with the patient.

While the bereavement support needs of spouses, carers and parents of children have been extensively investigated, little is written about the bereavement needs of other people outside a patient's immediate family. This study has highlighted that there are likely to be people within the terminally ill person's kinship networks who will be in need of bereavement support but would not normally be contacted or identified. Yet, little is known about the bereavement needs of this group or how it would be best to contact them, given different jurisdictional privacy laws. At this time, the only feasible option is that bereavement support information is provided to the patient and/or family to distribute to those who they feel may require additional support. Then, if contact is made with a bereavement service, referrals to specialist mental health and/or counselling professionals can be made when clinically indicated.

Limitations and strengths

Like all qualitative studies, the results of this study are not generalisable. These study findings may reflect the perceptions of a highly selective sub-group of palliative care in-patients, mainly people with advanced cancer. As such, this study not capture the views of people: living with advanced non-malignant disease; from culturally and linguistically diverse backgrounds; and/or Aboriginal and Torres Strait Islander people, which is a limitation. Other limitations are that the participating patients were all identified by their physician as meeting the inclusion criteria and were therefore, perceived to be comfortable about discussing matters relating to their impending death. In addition, all patients agreed to participate in the study; and finally, patients spoke freely about the people they were concerned about. As this was an unfunded study, screening and recruitment only occurred when the clinical trials nurse had capacity to conduct the interviews which extended the study timeline. During the pilot phase it was evident from the transcripts that at times it was challenging to keep the participant's focussed on answering the questions, with many taking

the opportunity to reflect more broadly on their life. The subsequent refinement of the open-ended interview schedule to initiate discussion and more targeted follow up questions as per stated schedule made the interviews easier to manage.

Despite these limitations, this study has many strengths. The heterogeneity of the patients that participated reflects the diversity that is evident in palliative care services with these patients all having different diagnoses, socioeconomic backgrounds and family structures. However, the age and predominance of a cancer diagnosis is reflective of the demographic profiles of Australians admitted to specialist palliative care inpatient services (Australian Institute Health & Welfare, 2019). The interviews were all conducted by an experienced nurse who had established a rapport with the patient well before the interviews commenced. A combination of rapport, knowledge of the patients and advanced communication skills is important in terms of ensuring that the patients all felt comfortable sharing their concerns.

Conclusion

There are potentially a group of community members who may be in need of bereavement support who otherwise may not be contacted by specialist palliative care services. Further work is needed to confirm these findings and to explore the views of friends and family nominated by patients on being contacted for information on bereavement support. Adopting a more person-centred approach may help bereavement counselling services which are often under-resourced, to be provided to the people who need it most. This research highlights the opportunity for experienced palliative care nurses to consider engaging people with palliative care needs in identifying people outside of their next-of-kin networks who may be in need of bereavement support. Replicating this study in other populations is important. It would seek the views of the people patients perceive to be in need of bereavement support before it is more widely embedded into clinical practice.

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