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Caring for people dying in acute hospitals: A mixed-methods study to examine relative's perceptions of care

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ABSTRACT

Objective: Improving the care provided for people dying in acute healthcare facilities has been identified as a priority for Australian healthcare. Previous observations support the idea that quality care improves outcomes for the dying person as well as for their relatives. To improve care it is essential that there be a clear understanding of which issues require attention. The aim of our project was to improve the understanding of the experiences of family members whose relatives had died on an acute medical ward.

Method: A mixed-methods approach was adopted for our study. With the approval of the human ethics committee, relatives were approached within three months of the death of their family member and invited to participate in an interview based on a quality-of-dying-and-death (QoDD) tool.

Results: Of the 50 families approached, 10 agreed to be interviewed. When they were asked to reflect on the experiences of the dying person, the issues that they articulated most strongly related to the need to have time before death to address issues and spend time with important others. With regards to the needs of the dying person's relatives, people articulated strongly that they needed information, support, and evidence of good symptom control. The provision of support post-death was also poignantly highlighted.

Significance of Results: This study supports observations made in other clinical areas that have identified that timely communication, good symptom control, and ongoing support for both the dying person and their family has important ramifications. Articulating such details is an important part of understanding which aspects of care require attention.

KEYWORDS: Relatives, Acute hospitals, Palliative care

INTRODUCTION

An increasingly robust body of literature confirms that outcomes are better when imminently dying patients and their families are well supported with quality care delivered with palliative intent (Levy et al., 2012). For example, the provision of such care for those facing imminent death has been shown to improve their experience of symptoms (Currow et al., 2008) while addressing the anxiety of both the dying person and their relatives (Abernethy et al., 2008). Supporting patients' relatives has been shown to ameliorate the stresses of caring, allowing them to move forward with their bereavement (Abernethy et al., 2008). While these facts are well understood in hospice and palliative care environments, the reality is that most people in developed countries like Australia do not die in such environments or in contact with such services.

Australian data suggest that up to 50% of Australian deaths occur in acute care hospitals, equating to approximately 75,000 deaths annually (Australian

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Institute of Health and Welfare, 2013). The majority of these deaths are expected, occurring as the result of chronic illnesses. Most recently, it has been estimated that approximately 60% of expected deaths would benefit from the input of palliative care (Murtagh et al., 2013), which in real terms suggests that 44,000 Australians might benefit from specialist palliative care during the final days of life. Despite the fact that palliative care services are well developed in Australia, it remains well beyond the capacity of the existing workforce to engage with this number of deaths (Australian Institute of Health and Welfare, 2013). This observation suggests that, in the absence of an agreed national minimum standard of care allowing all health professionals to understand what is the most appropriate care, there are likely to be large numbers of people dying with poorly controlled symptoms and unmet needs.

Considering this care gap requires not only service planning to enhance specialist palliative care capacity but also consideration as to how all health professionals can be equipped with the necessary core skills to initiate timely and appropriate care. Undertaking such a significant quality improvement program requires current practices to be documented. Only then can comparisons between usual and ideal practice be made so as to allow an understanding of the magnitude of changes necessary to reach an ideal state.

A recent audit of the actual care delivered in one of the two Australian hospitals highlighted that the actual care delivered would be unlikely to meet dying people's needs (Clark et al., 2014). Specifically, issues around communication with health professionals, approaches to assessing physical symptoms, and attention to minimizing care burdens suggested that people's needs were not likely to be addressed. In addition, prescribing practices were observably inconsistent and did not adhere to best practice as outlined in clinical guidelines. The audit highlighted that the documentation that supported the engagement of relatives in discussions was negligible, making it impossible to understand whether relatives' expectations were met or how they perceived the quality of care delivered.

This latter point prompted our project, which was undertaken with the intent of examining the experiences of relatives of people dying in Australian general medical wards. The importance of considering relatives' experiences has been explored in different care settings (McNamara & Rosenwax, 2010), including critical care (van der Klink et al., 2010) and hospice/palliative care (Abernethy et al., 2008; Stajduhar et al., 2010). There are scant data that describe the experiences of relatives with a family member who died on a general medical ward, despite this being the most likely place in a hospital for a person to pass away.

The aim of our present work was to document the experience of persons who had a family member who died on an acute medical ward. This was undertaken with the objective of identifying if there is a gap between consumer expectations and the actual care delivered. Such details would be a vital part of informing practice change.

METHODS

Study Design, Study Setting, and Participants

A mixed-methods prospective approach was adopted. After approval from the local human research ethics committee was granted, relatives of people who had died within the prior three months on a general medical ward of a regional teaching hospital (NSW, Australia) were approached by letter and invited to participate in an interview based on the Quality of Dying and Death (QoDD) Questionnaire (Levy et al., 2005).

Data Collection

Two researchers undertook the semistructured interviews, one to conduct the interview and the other to take notes. At the beginning of the interview, the interviewer explained the structure of the interview. Participants were then advised that they would be asked to numerically score the QoDD items. They were then informed that the interviewers would be interested to learn if they had other details to provide that would help the interviewers better understand what their experiences had been.

The QoDD questionnaire is a validated 31-item tool designed to capture people's perceptions of their relatives' experiences during their final week of life (Levy et al., 2005) (see Fig. 1). Most QoDD items are two-part questions. The first asks people to numerically score the frequency with which the dying person experienced different problems (0 = none of the time, 5 = all of the time), while the second asks people to rate the effect this issue had on the experience of dying. This is summarized by a numeric rating where 0 is defined as a terrible experience and 10 as an almost perfect experience (Fig. 1). The final scores are rated on a 0-to-100 scale where higher scores reflect relatives' perception of a better quality of death. Second, participants are invited to add any details, in their own words, that would provide researchers with any details they deem would best allow the interviewers to understand how the whole experience was for their relative.

1. How often did XX appear to have pain under control? 0–5
2. How often did XX have control of what was going on around them?
3. How often was XX able to feed himself/herself?
4. How often did XX have control of his/her bladder or bowel?
5. How often did XX breathe comfortably?
6. How often did XX appear to be at peace with dying?
7. How often did XX appear to be unafraid of dying?
8. How often did XX laugh and smile?
9. How often did XX appear to have the energy to do most things he/she wanted to?
10. How often did XX appear to be worried about strain on his/her loved ones?
11. How often did XX appear to keep his/her dignity and self-respect?
12. How often did XX spend time with his/her spouse or partner?
13. How often did XX spend time with his/her children?
14. How often did XX spend time with other family and friends?
15. How often did XX spend time alone?
16. How often did XX spend time with pets?
17. Did XX appear to find meaning and purpose in life?
18. Was XX touched or hugged by loved ones?
19. Did XX attend any important events (e.g., weddings, graduations, birthdays)?
20. Were all of XX's healthcare costs taken care of?
21. Did XX say goodbye to loved ones?
22. Did XX have one or more visits from spiritual advisers?
23. Did XX have a spiritual service or ceremony before his/her death?
24. Was a mechanical ventilator or kidney dialysis used to prolong XX's life?
25. Did XX have the means to end his/her life if he/she needed to?
26. Did XX clear up any bad feelings with others?
27. Did XX have his/her funeral arrangements in place prior to death?
28. Did XX discuss his/her wishes for end-of-life care with his/her doctor? For example, resuscitation and intensive care?
29. Where did your loved one die?
30. Was anyone present at the time of death?
31. In the moment before death, was he awake or asleep?

Fig. 1. Stems of the QoDD tool.

Analysis

Respondent characteristics and the results of the QoDD questionnaire were summarized using descriptive statistics. The transcripts were read through to appreciate the whole document, which was then examined in more detail. The responses made to the individual items were examined, and then the responses to the open-ended questions were examined. This allowed themes from the relative's experiences to be extracted.

RESULTS

Respondents

In one three-month period, 50 deaths occurred on the medical ward. Letters were sent out to the person who had been identified as the one to contact from a deceased patient's files. Ten people replied to these letters, all providing their consent to be contacted and interviewed. Interviews were conducted in a place chosen by the interviewee; three preferred their home and the rest settled on an outpatient clinic at the hospital. The interviews ranged in length from 45 minutes to 2 hours. Interviewees were predominantly women ($n = 9$), half of whom had been married to the decedent. Despite the time from death, interviewers reported that all interviewees highlighted their grief, which at times made the interview process emotionally difficult for all involved.

Quantitative Results

The group mean QoDD score relating to the impact that issues had on quality of death and dying was 68.64 ($SD \pm 16.41$). However, when all possible items were considered, only 133 items out of a possible 310 were completed (43%). In contrast, 230 (74%) commentaries were offered.

Qualitative Questionnaire Results

The two sets of answers were examined by two authors (KC and NB). First, the comments made on the QoDD items were reviewed. At the beginning of an interview, people were invited to make further comments only after they had completed the two aspects of the QoDD tool. It was notable that so many of the QoDD items prompted comments. Reflecting the stems of the question, the majority of comments were framed in the third person, adopting language such as "he" or "she." The items that provoked half or more of the participants to make comments are summarized in Table 1.

The open-ended questions introduced at the beginning of the interview to follow the QoDD items were largely framed with respect to how the experience affected the person being interviewed. This point was highlighted by the language, as people tended to employ the first person (e.g., "I" or "we"). These comments offered insight into issues that the relatives perceived to be personally important as they coped with the death of a family member and its aftermath. It was possible to extract six specific themes, summarized below.

Theme 1: Communication with Family Around Goals of Care

Half the group interviewed made mention of the degree of communication around the goals of care for their dying relative that they or the patient had engaged in with health professionals. Some of the comments were positive:

> I look back on the way we were treated with respect and compassion. A young doctor in Emergency spoke with us and helped us to understand what was happening.

Another relative noted, "The doctors asked what his wishes were and tried to honor them."

Other examples were less positive. One family spoke at length on how problematic they found the experience of trying to speak with health professionals: "It was difficult to get answers; they said he had to leave the hospital, but he couldn't." This relative then described ongoing difficulties:

> A nurse said, "We don't talk to families on Sundays." We complained and a family meeting was set up, but no one turned up except for us. I asked to speak to the doctor again, and they said I had to contact him, but they would not give me the contact details. It was like a Monty Python skit.

Another family voiced similar frustrations:

> I found it hard to get answers from the nursing staff, and the doctors were not very good at explaining what was going on. We asked to see a doctor one night, and the nurse told us we would not get a doctor that night. This surprised us because he was so unwell and in a hospital.

Theme 2: Communication with Family that Death was Imminent

Half the relatives interviewed identified that they did not perceive themselves as having had discussions with health professionals who used language that helped them understand that death was imminent. For some, the comments had an angry tone: "We thought his prognosis was 6–12 months; we did know he was going to die; they did not tell us." Another family member noted, "They reassured us that he would be kept comfortable. No one said he was dying!"

Being aware that death was imminent was highlighted as important, as it would allow those important to the family to be there: "Everyone [i.e., health professionals] talked a lot, which kept us from him, but no one said he was dying." This was reiterated by another: "We thought he was dying, but people [i.e., the social worker] kept talking to us about issues such as his comfort. Because of the conversations, we missed his death."

Theme 3: Place of Death

Although all the patients related to interviewees died in hospital, for two thirds of the group there was a sense of suddenness. The fact that their relative had died in hospital rather than at home without being given a choice was of concern. One family member commented, "Place of death was never discussed, but he wanted to be at home." Another commented that they did not know why their relative was even *in* the hospital: "I don't know why they sent her to hospital; that was not her wish."

Another variation on this theme was the fact that some felt their plans had been ignored and patients forced to die in an acute care setting when their wish had been for a palliative care unit: "We wanted him to die in the hospice, but the referral was made too late, and he could not be moved." Another stated, "Palliative care said he was not ready for hospice yet. But there was a rapid change and suddenly he could not be transferred to the hospice as he was too sick. I felt disappointed by this."

Table 1. *Specific QoDD items where five or more respondents offered comments*

Item (Number of People Commenting)	Positive Perceptions of Experience	Negative Perceptions of Experience
Having pain under control ($n = 6$)	"They said he was not in pain, but he was." "He was on constant morphine; he was comfortable and this was good." "She never complained of pain." "Pain well managed."	"They said he was not in pain, but he was." "They tried but the pain was never well controlled. Palliative care only came on the last day. It was too late by then."
Having control of the event ($n = 5$)	"He was in control."	"He had no control. He was confused and wanted me there." "I saw her in the ED, and then she died; I don't know if she was in control." "He had no control; he was too weak." "He was unconscious by the time we got there; he had no control."
Having control of bladder and bowels ($n = 6$)		"No control; had to wear a nappy. He was upset and agitated over messing himself." "He was struggling with this and it played on his mind." "He had control of his bladder but they just put pads on him. He did not need it." "He was very distressed; they put a catheter in, but he wanted to use the pan. They would not let him, and this upset him." "She was incontinent if they did not help her; she needed help." "Constipated but had a bag for his bladder."
Having energy to do things one wants to do ($n = 6$)		"He was unable to do things, and this frustrated him." "He had no energy." "No energy, he was dying." "He was weak with no energy." "No, he had no energy." "He was fatigued but able to signal his will with his right hand."
Spend time with your children as much as you want ($n = 6$)	"His children were always around." "Each child spent time with him; this was special and important."	"His son lives OS. They were here recently and he saw them a lot. He cried when they left. His son completed his happiness." "No, his son visited and then left. He went down very quickly and did not have a chance to see his son again," "I think he would have liked to see them, they were estranged from him." "Not while he was conscious; this is one of my regrets. None of the family were able to get there before he was unable to talk." "His kids visited from overseas before; they spoke on the phone."
Be touched and hugged by loved ones ($n = 6$)	"His brother was close to him." "He always wanted to hold my hand." "We had a private room and that allowed us to be together, holding hands."	"I slept over night at the hospital; I wish I had been able to hold him." "His pain was too bad for me to touch him." "He held my hand; I wanted to hold him."

Continued

Table 1. *Continued*

Item (Number of People Commenting)	Positive Perceptions of Experience	Negative Perceptions of Experience
Say goodbye to loved ones	"He said goodbye." "The doctor spoke to him so he knew and could say goodbye."	"He was sedated on the last day; we could not talk." "He could not say goodbye; it was too upsetting." "They rang me and said she died; I did not say goodbye." "He did not know; he was shocked when they mentioned hospice." "He did not know."
Discuss wishes for EoL care with doctors ($n = 7$)	"He made decisions not to have treatment."	"Palliative care spoke about this; I wish they had not as he was terrified. He did not ask to have this conversation." "I don't know, we did not talk about it." "The doctors told him how bad things were but did not speak to us. I did not like this because he was never able to speak to us again after they told him he was going to die." "I was a bit annoyed as she did not wish to go to hospital; she had indicated she did not want CPR and just wished to stay at home." "He was in denial and the doctors said this, too." "He did not want it dragged out as he did not want the pain to go on. He was told there were medications for pain. He said to the doctor, 'You told me there would not be pain but the pain was very bad for him.' "
Location of death (home, hospice, hospital)	"He wanted to stay where he was." "He wanted to be at home but accepted where he was." "He wanted to die at home; I wanted him to go to the hospice. In the end, he was adamant he should be in the hospital."	"No other options available." "He wanted to transfer to the hospice, and I wanted this to. He was too unwell and I felt cheated." "He wanted to be at home." "She was in a four-bed room; if we knew she was that bad, we would have taken her home."
Die with/without loved ones present	"I was there when he died. I was glad of this as our daughter died alone." "He passed away just before I came back into the room. His sisters were there so he was not alone." "I was there and that's important." "We were there for him." "His sisters said goodbye the day before. I was there."	"No one was there."
Avoid worry about strain on loved ones		"He always worried about me." "Yes, very worried about me." "He just wanted to be at home with me." "He was constantly worried about this." "She would not do anything to make herself a burden on me." "He did not want to bother people; in hospital he had three falls. I did not like the forceful style they used." "He was worried we had it hard."

Theme 4: Families Concerns Around Loss of Dignity

The most common issue highlighted by families as representative of loss of dignity involved problems with incontinence and how much patients disliked this situation. Relatives' stories focused on the need for people to be put into nappies, accompanied by comments illustrating how they felt their relative's privacy had not been respected: "One day we went in and he had a nappy on, but he had nothing to cover him up, no sheet, and the curtain was open." Another interviewee stated, "He was put in a room with three women, and he wanted to use the bathroom. On the last day, they put a pad on him, and we knew he would have hated that."

Theme 5: Symptom Control

Not only pain, but confusion and breathing problems were mentioned in response to the open-ended question, confusion being mentioned most often. These comments focused on the fact that families were worried about the prospect of the dying person harming themselves: "He was unconscious but moving around a lot; we were worried he would hurt himself." Another family member reported, "He was very agitated," and another, "She was delirious and too heavy for the nursing staff."

Theme 6: Support for the Family and Followup

The majority of families interviewed indicated they would have appreciated either more support when the person was dying or at the time they were interviewed (i.e., three to four months after the death). Interestingly, the support that people wished for was very practical, including a need for rest and sustenance: "We were not offered beds to sleep in the room"; "Once the café closed, there was no place for us to eat."

Other comments reflected more on people's needs for support after the death: "I have not had any counseling; I think I fell through the cracks. I cannot get through the day without the feeling that I cannot breathe"; "No bereavement support, and palliative care was too late."

DISCUSSION

Our study provides some insights into the experiences of the relatives of people who died in an acute care hospital setting. Similar to previous observations is the fact that relatives strongly reiterated that they, like their dying relatives, have complex needs in terms of information and support.

It was interesting to observe that, while some of those interviewed were able to numerically score QoDD items unprompted, more people answered the first part of the question, which they then tended to elaborate on with more comment rather than a numerical rating. It is acknowledged that this is not the usual approach to using this tool, but the results are interesting and provide some insights that a numeric score might not offer by itself. This statement is based on the fact that, although people detailed concerns, the numerical scores were reasonably high, with higher QoDD scores being reflective of positive experiences. This seemingly paradoxical observation has been noted elsewhere with the use of a QoDD tool and has been attributed to the difficulties that people have when scoring such complex issues (Curtis et al., 2013).

Examining the comments made around the QoDD questionnaire reveals that people used this time to highlight their thoughts as to how their relative would have experienced the issue. Most attention was paid to the fact that those interviewed believed that the dying person had wished to spend as much time as possible with people important to them, including family members and friends. Separate but closely related was that some respondents stressed the fact that their now-deceased relatives placed great importance on having sufficient energy to undertake such tasks as spending time saying goodbye to those important to them and talking with their doctors. The sharing of such details is valuable when planning care delivery. This highlights that discussions around prognosis when death is expected need to be conducted in a timely fashion.

The open-ended question at the end of the interview revealed six recurring themes. These were interpreted by the researchers as being related to issues that were deemed personally important to the now-bereaved interviewee. Again, issues around communication were raised that focused on families' needs to understand what was happening to the dying person, including the fact that death was imminent. It is noteworthy that this is a difficult diagnosis for health professionals to make, and an even harder one for laypeople. Many may never have experienced death, and, as highlighted by these families, some will need guidance to understand that this is what is happening.

Other major issues highlighted by families included their clear statements around the fact that they felt a need for greater support. During the time of death, this appeared in the form of a need for practical support to allow them to stay with their relative. To achieve this is, people articulated that they needed places to rest and eat. However, after death, people identified a need for personal support to allow for better grieving and the ability to move forward with their lives. There is no doubt that the state of being bereaved is one of the most emotionally challenging experiences of human existence (Bryant et al., 2013). Aside from grief and sadness, being bereaved predisposes one to significant morbidity and, in the worst cases, mortality (Buckley et al., 2012). On a physiological level, intense grief has been shown to be associated with increased cortisol secretion, which can result in such problems for the bereaved as sleep disturbances, altered immune responses, and prothrombotic responses, highlighting the notion of bereavement as a public health issue (Buckley et al., 2012). This is especially true when the protective effects of increased social support for bereaved individuals are considered (Christakis & Iwashyna, 2003). This raises the question of whether it is the responsibility of health services to ensure that all have easily accessible bereavement care. This is in contrast to the current Australian situation, where bereavement services tend to be offered only to relatives of people who died in contact with palliative care services.

Poignantly, families clearly articulated that they wished their relative to be protected, that they wished to ensure appropriate care and optimum symptom management. The most oft-mentioned symptom was confusion. This observation is consistent with the results of other studies (e.g., Bruera et al., 2009), who found that delirium, though common at the end of life, is most distressing for families and staff members. Although this is a common occurrence, it continues to be identified as one that is poorly diagnosed and poorly managed despite the ready availability of clinical guidelines to help inform practice (LeGrand, 2012). It is notable that best practice includes nonpharmacological approaches, which provides opportunities for families to be educated around the problem and to participate in the caring process. This work highlights a real need for such strategies to be better understood and incorporated into acute care medical units.

STRENGTHS OF THIS WORK

Our work highlights that 20% of the families of people who have died on medical units have experienced issues around the care delivered to the dying person and the support offered to themselves. The information provided by these families offers insight into consumers' perspectives, establishing a baseline from which to implement and monitor changes. In addition, the willingness with which families engaged in this process establishes an encouraging precedent that can help inform future work.

WEAKNESSES OF THIS WORK

A pragmatic decision was made to limit the interviews to the families who agreed to participate; therefore, saturation was not attained. Additionally, the interviews were not taped. It is possible that other relevant comments may have been made that were not captured.

Although the QoDD questionnaire was the basis of our work, the way it was employed by participating families has not been previously reported. It is not clear if the way people chose to respond was because of the way the interviews were conducted or if the group who agreed to be interviewed had predetermined views that they wished to air. Despite this, the richness of the data collected as a result is seen as highly valuable, though unexpected. Further work to explore this will be necessary.

IMPLICATIONS FOR FUTURE RESEARCH

This work is the basis for a stepped trial to implement an approach to caring for dying people in acute care hospitals in regional Australia. The process conducted here will be repeated at each site and then again at the conclusion of the trial period, allowing objective comparisons to be made.

CONCLUSION

This report highlights the feasibility of talking with bereaved relatives in order to understand their experiences. The mixed-methods approach allows objective tracking of whether there are improvements in people's perceptions while also understanding in more detail the complexity of people's experiences. Establishing such baselines is imperative for projects aimed at improving the quality of care delivered to dying people.

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REFERENCES

Abernethy, A.P., Currow, D.C., Fazekas, B.S., et al. (2008). Specialized palliative care services are associated with improved short- and long-term caregiver outcomes. *Supportive Care in Cancer*, *16*(6), 585–597.

Australian Institute of Health and Welfare (2013). *Palliative care services in Australia, 2013*. Canberra: AIHW.

Bruera, E., Bush, S.H., Willey, J., et al. (2009). Impact of delirium and recall on the level of distress in patients with advanced cancer and their family caregivers. *Cancer*, *115*(9), 2004–2012.

Bryant, R.A. (2013). Is pathological grief lasting more than 12 months grief or depression? *Current Opinion in Psychiatry*, *26*(1), 41–46.

Buckley, T., Sunari, D., Marshall, A., et al. (2012). Physiological correlates of bereavement and the impact of bereavement interventions. *Dialogues in Clinical Neuroscience*, *14*(2), 129–139.

Christakis, N.A. & Iwashyna, T.J. (2003). The health impact of health care on families: A matched cohort study of hospice use by decedents and mortality outcomes in surviving widowed spouses. *Social Science & Medicine*, *57*(3), 465–475.

Clark, K., Byfieldt, N., Green, M., et al. (2014). Dying in two acute hospitals: Would usual care meet Australian national clinical standards? *Australian Health Review*, in press.

Currow, D.C., Ward, A.M., Plummer, J.L., et al. (2008). Comfort in the last 2 weeks of life: Relationship to accessing palliative care services. *Supportive Care in Cancer*, *16*(11), 1255–1263.

Curtis, J.R., Downey, L. & Engelberg, R.A. (2013). The quality of dying and death: Is it ready for use as an outcome measure? *Chest*, *143*(2), 289–291.

LeGrand, S.B. (2012). Delirium in palliative medicine: A review. *Journal of Pain and Symptom Management*, *44*(4), 583–594.

Levy, C.R., Ely, E.W., Payne, K., et al. (2005). Quality of dying and death in two medical ICUs: Perceptions of family and physicians. *Chest*, *127*(5), 1775–1783.

Levy, M.H., Adolph, M.D., Back, A., et al. (2012). Palliative care. *Journal of the National Comprehensive Cancer Network*, *10*(10), 1284–1309.

McNamara, B. & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science & Medicine*, *70*(7), 1035–1041.

Murtagh, F.E.M., Bausewein, C., Verne, J., et al. (2013). How many people need palliative care? A study developing and comparing methods for population-based samples. *Palliative Medicine*, *28*(1), 49–58. Epub ahead of print May 21.

Stajduhar, K.I., Martin, W. & Cairns, M. (2010). What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative & Supportive Care*, *8*(3), 277–289.

van der Klink, M.A., Heijboer, L., Hofhuis, J.G., et al. (2010). Survey into bereavement of family members of patients who died in the intensive care unit. *Intensive and Critical Care Nursing*, *26*(4), 215–225.