

Nurses supporting life-partners conversations about end-of-life care wishes: a literature review for guidelines

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KEY WORDS

end-of-life, conversations, life- partners, nurses, palliative care

ABSTRACT

Setting

Nurses providing end-of-life care.

Objective

A literature review was conducted to establish what guidelines are available for nurses to encourage discussions between life-partners about end-of-life care wishes.

Subjects

Life-partners and nurses

Primary argument

This literature review located articles that addressed the impact terminal illness, culture and established communication patterns have on end-of-life discussions for the broad group of family members and carers. Articles generally presented the challenges doctors, nurses and other health care professionals face in speaking about end-of-life care wishes with patients, carers and family members. However, articles relating to conversations specifically between life-partners about end-of-life care wishes were not evident. This is surprising because frequently the life-partner is the primary care giver during the end-of-life care phase of a life limiting illness. Furthermore, literature indicates life-partners who are able to speak freely about most life issues adjust better to the challenges that events such as illness, may present to them as a couple.

Conclusion

By using the main themes identified within the literature review from discussions held by family members, nurses and health professionals it may be possible to develop guidelines for life-partners. The use of a guideline may assist nurses in encouraging life-partners to have conversations about end-of-life care wishes. This will not only acknowledge the uniqueness of the relationship between life-partners, but also contribute to providing holistic patient centred care for each couple.

INTRODUCTION

In Australia health facilities and organisations have increasingly encouraged the general public to engage in open conversations about end-of-life care wishes (Advance Care Planning Australia 2014). In particular through the Respecting Patient Choices Program, an initiative of the Palliative Care Branch of the Australian Department of Health and Ageing at Austin Health in Melbourne, Victoria (Advance Care Planning Australia 2014). This program has since been widely adopted by many health care facilities throughout Australia. Such programs have been pertinent since authors such as Browning (2008) identified one of nurses' greatest frustrations in providing end-of-life care occurs when family caregivers are unsure of their loved one's wishes and are therefore indecisive when consulted. Stephenson (2010) explains that end-of-life care is provided for a patient whose disease process has progressed, the health of the patient has declined and it is evident that the patient is in the final stages of the illness prior to death. Whilst the beginning of this stage of illness can be easily identified for some patients, for others subtle changes may occur over an extended period of time particularly if the disease process is of a chronic nature (O'Connor et al 2012). Advance Care Planning Australia (2014) describes that an Advance Care Directive as:

'a written document that records the medical treatment wishes of a person, which can then be used if a person is unable to speak for themselves due to illness or injury. The document may also appoint a substitute decision maker and include non-medical wishes for end-of-life such as spiritual care.'

It is estimated that up to 50% of Australians will not be able to make or express their own decisions when they are near death (Advance Care Planning Australia 2014). The appointed proxy needs to be the person who has the best interests of the patient foremost in mind and who is willing to advocate on their behalf (Advance Care Planning Australia 2014). Where a life-partner is present it is likely that they will be the appointed proxy. Literature related to life-partners conversations about end-of-life issues appears to be scarce. Hence, the search was widened to explore what has been published about families and health care professionals' conversations. Searches were conducted using the Medline, Pubmed, CINAHL and OvidSP databases. A combination of search words including 'communication', 'death', 'family', 'advanced directives' and 'terminal' were used. Collectively these searches yielded 580 articles. The parameters guiding all searches included: full text, peer reviewed articles in the English language published between 2003 and 2012. Following the reading of abstracts, 51 articles were retained. After reading of the full text, 28 articles were excluded from the review as they did not specifically relate to conversations about end-of-life care wishes. Subsequently it was identified that one article was common from three databases in the final selection of 23 articles, this redundancy reduced the sample to 21 articles. The articles excluded from the final selection did not make any direct connection to discussions between family members, health professionals and the patient about end-of-life care wishes. For example, articles relating to communication between health professionals only, articles exploring end-of-life care and palliative care in general terms only, and studies and discussions in the use of Advance Care Directives with no reference to communication in specific terms were excluded from the enquiry. Four different themes were identified from the selected articles. These were: the impact of terminal illness on family communication; the impact of culture; established communication patterns within the family; and the challenges encountered in communicating with health care providers about end-of-life care issues. This paper goes on to explain how these themes may be applied in developing guidelines for life-partners to encourage conversations about end-of-life issues.

DISCUSSION

Conversations between life-partners

Lyons (1978) explores the typical functioning structures of conversation within a marital relationship, recording how changes occur in the developing relationship and through a couple's life journey. This work indicates that communication between life partners does not remain static. Instead, it is an evolving mechanism within the relationship influenced by life events and other relationships (Lyons 1978). One example of such an event may be the occurrence of a terminal illness. This unplanned interruption in a couple's life plans may allow little time for emotional and psychological adjustment. Dakof and Liddle (1990) established that life-partners who were able to talk freely with each other about their illness were more likely to adapt to the changes that would occur than couples who did not converse openly. In a study Sanford (2003) conducted with 37 married couples, 24 different topics were identified as being difficult topics to converse about within the relationship. It is interesting that this list did not include conversations about end-of-life. An implication of this could be that in general, life-partners are concerned with living everyday life rather than considering the need to contemplate and communicate about the possibility of separation through death. This highlights the challenge for nurses and other health care professionals in supporting life-partners, when they are dealing with the reality of facing a life limiting illness.

The demands of care giving

Melin-Johansson et al (2012) acknowledge that the primary care giver is often a close relative of the patient. In general, if care is being provided in the home this caregiver is consumed with the tasks of caring for their loved one, taking on roles not previously filled within the relationship for example navigating through a foreign health care system and dealing with their own physical and existential needs (Melin-Johansson et al 2012). The pressure of attending to such pressing practicalities reduces the opportunities for conversations about end-of-life care wishes between the patient and carer. If an Advance Care Directive is not completed nurses may be required to care for patients without any clear direction about the patients' wishes about their end-of-life care during the final stages of an illness. A dilemma may occur in trying to encourage these conversations at a time when the life-partner as the primary care giver is exhausted and not willing or knowing how to initiate such difficult discussions. Kanacki et al (2012) supports this, reporting that research in both pre-and-post death studies of married couples where one partner is primary carer found that the experience was profoundly life changing. In addition many of the participants reported these experiences were often too painful and distressing to talk about freely (Kanacki et al 2012).

The influence of family communication patterns

Many commentators agree that open communication between family members has positive outcomes in providing patient-centred care, which assists in addressing the end-of-life care wishes of the patient (Wittenberg-Lyles et al 2012; Del Gaudio et al 2011; Browning 2008; Gauthier 2008; Pautex et al 2008; Kahana et al 2004; McDonald et al 2003). However, these articles fail to provide insight into how life-partners can initiate difficult conversations with their loved one about end-of-life care wishes. This was confirmed by McDonald et al (2003) in a study of 119 participants including health care professionals and family members. Many subjects were unable to provide suggestions on how to improve open conversations with families. Benkel et al (2012), found that ultimately, the patient and caregiver may have different needs at different times, making conversation around the impending death difficult. Gardner and Krama (2009) reported a number of patients wished to speak more about their approaching death but refrained from doing so with their life-partner because they thought it would be too upsetting. Reluctance to upset one's partner might explain the finding of Kahana et al (2004), where single older adults were more likely to have discussions with other family members than were married older couples. Moorman (2011) explains this further, recording some older patients felt their spouse

understood their wishes well and therefore, in-depth conversations were not needed. In contrast, following the death of their loved one, a number of spouses expressed some doubts to whether their understanding of their loved one's wishes had been correct (Moorman 2011). Benkel et al (2012) suggest conversations are more likely to focus on the practical issues such as, treatment, care options, and funeral arrangements when loved ones are faced with the diagnosis of a life limiting disease. Braun et al (2006) provide results of a study in which a group of carers were provided with a series of five educational booklets to help improve their understanding on topics including: Advance Care Planning; how to plan for the funeral; what to do at the time of death; saying goodbye; and the bereavement journey. It was found that caregivers who were actively engaged in providing care for a loved-one at home were more likely to read the booklet relating to preparing to say goodbye which included information about common symptoms experienced by a patient during the end-of-life phase of an illness. This booklet also provided suggestions on how to make their dying loved one more comfortable. Topics included in this section may provide a valuable framework for nurses and other health professionals in directing life-partners' conversations about specific end-of-life care wishes.

Links between communication, family stress and terminal illness

Some articles described the stresses the family caregivers experience when faced with caring for a loved one with a terminal illness. Del Gaudio et al (2011) explain many families make the adjustment of living with a life limiting illness well despite many difficulties, while others find this occurrence exceptionally stressful. For example, families with a history of conflict can experience an exacerbation of family discord when a life-threatening illness occurs (Del Gaudio et al 2011). Erlen (2005) highlighted that while Advance Care Directives are designed to protect the patient's autonomy in decision-making, the family caregiver and others may not always agree with the expressed wishes of the patient. In some cases the family may try to influence the patient's wishes, however,

'in some states, such as Queensland, South Australia and the Northern Territory, an Advance Care Directive is a legally binding document. In other states Advance Care Directives may still be valid, and therefore persuasive to some extent, under common law (Harris 2008).

All states and territories in Australia have an Office of Public Advocate, or a similar independent statutory body whose role is to provide support in the event of an Advance Care Directive being disputed (Office of Public Advocate of South Australia 2013; Office of Public Advocate, Victoria)

The family caregiver may also experience the need for self-protection as well as feeling compelled to restore relationships that have not been harmonious in the past (Erlen 2005). These authors suggest such stress can prevent conversations within the family around the issues of the patient's end-of-life care wishes. However they do not discuss specific stressors that life-partners may experience within their relationship related to communicating about these challenging topics.

Impact of culture on communication between life partners

Blank (2011) explains that culture defines the way in which communications occurs around impending death, the meaning of declining health and any related distress. In broad terms, culture is a "constellation of shared meanings, values, rituals and modes of interacting with others that determines how people view and make sense of the world" (Kraukauer et al 2002). Hinders (2012), Johnstone and Kanitsaki (2009), Ko and Lee (2009) all agree that in some cultures it is neither acceptable nor appropriate to discuss matters related to dying, and therefore, it may be unreasonable for the family to discuss such topics with the patient. These articles shed no light upon the ways in which cultural norms may constrict communication between life partners in specific terms and provides no specific clues for nurses and other health professionals in knowing if or how to approach or encourage cultural appropriate discussions between life-partners.

Communication between health care professionals the patient and family

Goldsmith et al (2011) acknowledge acquiring the skills to communicate sensitively with family and patients around the difficult topic of dying is challenging for health professionals. A number of articles pertaining to open and honest communication between the patient, family and health professionals were reviewed (Sessanna and Jezewski 2008; Ingalls 2007; Tuttas 2002). Ingalls provides an overview of the holistic approach health care professionals can adopt to foster effective end-of-life discussions with the patient through exercising empathy, being present, and applying good self-care. Tuttas (2002) suggests that in particular, nurses need education around how to initiate conversations with patients. Topics for such education would include being in tune with when, and how, the patient may wish to speak about dying. It is possible that some of these strategies, focused as they are upon the health professional rather than the patient, may be useful when it comes to fostering communication between the patient and life-partner. In their systematic review of Advance Care Directive decision making, Sessanna and Jezewski (2008) identified that the majority of older adults were comfortable in discussing end-of-life care wishes with nurses and other health care providers. However nurses and health professionals were less likely to have these conversations with the older person yet no reason was reported for this not occurring (Sessanna and Jezewski 2008). Hinders (2012) suggests that some medical staff do not feel comfortable speaking about the impending death with the family caregiver, patient and significant others, resulting in these conversations not always occurring. This may also be the case for some nursing staff, despite a myriad of information pamphlets and brochures being widely available from many organisations in Australia. Again, these articles primarily focus on communication between the health professionals and family members, the care giver and health professionals and the patient and health professionals, rather than specifically between the patient and their life-partner.

As demonstrated there is a need for guidelines to be developed specifically for life-partners. This guide could firstly explain what an Advance Care Directive is, what is meant by the term end-of-life and the importance of life-partners' having an Advance Care Directive in place. The document could then suggest ways in which the couple can discuss end-of-life care wishes together.

RECOMMENDATIONS

Evidence suggests topics within guidelines for life-partners could include answers to questions such as:

- What is end-of- life?
- What is an Advanced Care Directive?
- Why is having an Advance Care Directive in place important?
- Why are conversations about end-of-life care wishes important for life-partners?
- When and where life-partners can talk together about these important topics?
- How often these conversations could occur?
- How to start conversations about end-of-life care?
- How to seek support from family to allow private time for these discussions to occur?

In addition, a list of potential topics for discussion between life-partners could be provided. These may include:

- wishes relating to preferred site of care;
- discuss any competing demands that the life-partner as the primary caregiver may have;
- support services that are available for home based care and what services are acceptable for both life-partners;

- common symptoms of distress that may occur at end-of-life and how to manage these;
- understanding normal responses to loss of health;
- spiritual needs and wishes;
- financial and legal arrangements and wishes; and
- funeral arrangements.

CONCLUSION

With the emergence of Advance Care Directives and other documents encouraging patients, carers and family members to discuss end-of-life care wishes, nurses and health care professionals are aspiring to provide holistic patient-centred care. This literature review has identified that whilst many guidelines are available to the public relating to end-of-life care there is a gap in information being provided specifically for life-partners. This review has demonstrated that by drawing on broader approaches and challenges for other carers a set of guidelines could be developed for life-partners to assist them in discussing the difficult topics relating to the end-of-life care wishes. In providing customised guidelines the unique relationship that exists between life-partners is acknowledged. Nurses and other health care workers providing end-of-life care are well positioned to foster these conversations between life-partners by utilising such guidelines.

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