

Preferences for place of care and place of death:

What, how, when and who to ask?

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Disclaimer statements

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Abstract

As healthcare systems worldwide are confronted with increasing numbers of ageing and terminally ill patients, the topic of where people want to spend their last days has received considerable attention. However, the strategies that researchers and clinicians use to capture these end-of-life views vary greatly in four key questions. These include: what, how, when and who to ask about location preferences. We will argue that how researchers and clinicians choose to answer these questions directly influences their findings. Based on these considerations, we will highlight ways to improve future palliative care and empirical end-of-life studies by addressing the precision, methods, timing and sources of preference assessments. Only when we are able to accurately identify where people want to spend their last days, can we begin to meet the needs of patients as they approach the final stage of their lives.

Keywords

Patient preference, informal caregivers, palliative care, place of care, place of death, preference assessments

Just as our living environment influences our quality of life, so does our dying environment influence how we experience death. Across the world, questions regarding where people are spending their last days have received considerable attention in recent times (Bone et al., 2017; De Roo et al., 2014; Loh et al., 2015; Teno et al., 2013). Confronted with increasing numbers of ageing and terminally ill patients, healthcare systems are under tremendous pressure to deal with the complex and prolonged care needs of those facing the end of life. The World Health Organization (2004) urged that “policy-makers should encourage the health services to inquire of people their preference for place of care and death. Meeting individual preferences should be the ultimate measure of success” (p. 17). To do this, however, we need to find ways to accurately assess people’s preferences and this may sound easier than it is.

The strategies that researchers and clinicians use to examine where people want to be at the end of life vary greatly in regard to four key questions. These concern: what, how, when, and who to ask about location preferences. The ways in which researchers and clinicians choose to answer these questions directly affect their findings. In this article, we will discuss these methodological considerations and identify areas of improvement for future studies and medical practice.

Precision of Preference Assessments – What to ask?

Communication is a central part of end-of-life care. Many patients and family caregivers want more information about their illness and its progression (Evans et al., 2009; Gallagher & Krawczyk, 2013; Jenkins, Fallowfield, & Saul, 2001). Yet, talking about death and dying is not easy for anyone involved and, therefore, often avoided (Galushko, Romotzky, & Voltz, 2012; Hancock et al., 2007; Munday, Petrova, & Dale, 2009). In this context, “What to ask?” may seem like a trivial question. When we are interested in where people want to spend their last days, we could simply ask them that. Unfortunately, it is not quite that easy. Agar et al. (2008) highlighted the rarely acknowledged distinction between preferences for place of care and place

of death. In a longitudinal study of 71 palliative care patients and their families, Agar et al. (2008) found that congruence between the two questions was low and that, as death approached, people were less often asked about their preferred place of death and more about place of care, arguably because it was less confronting. Based on this, Agar et al. (2008) suggested that these are two different concepts and using the terms interchangeably can lead to misinterpretations, confusion and uncertainty about people's actual preferences. Yet, researchers and clinicians often do not recognize this distinction, which is an essential first step to accurately examine location preferences at the end of life.

Methods of Preference Assessments – How to ask?

Methods of preference assessments also vary considerably between studies, from self-administered questionnaires, face-to-face or telephone surveys, semi-structured interviews, to chart reviews. It is important to acknowledge that different methodologies can lead to different results as each approach has specific advantages and disadvantages. For example, quantitative surveys can be cost-effective, anonymous and easy to administer. Yet, especially at the end of life, patients may be too ill and family members too distressed to complete lengthy questionnaires (Wiegand, Norton, & Baggs, 2008). Surveys also tend to oversimplify the complexities and dynamics of a person's life by focusing only on predetermined questions and answers (Dougall, Russell, Rubin, & Ling, 2000).

To avoid this reductionism, qualitative methods have been found useful (Dougall et al., 2000; Wiegand et al., 2008). Especially when addressing emotionally loaded and multi-layered decisions regarding one's own or a loved one's death, interviews provide a level of flexibility and depth seldom reached in multiple-choice questionnaires. Researchers and clinicians can prompt for information, follow-up on what was said and clarify questions if necessary. However, as with quantitative surveys, qualitative interviews can also be time-consuming and hence draining for frail patients. In addition, the strong involvement of the researcher may cause

interviewer biases (Hughes, 2008). In this regard, social desirability is a particular concern in face-to-face interviews where respondents might modify their answers to present themselves in a certain light (Fisher, 1993; Holloway & Wheeler, 2013). Batchelor, Owens, Read, and Bloor (1994) addressed this in a discussion paper on measuring satisfaction with healthcare services. They pointed out that care recipients may be unwilling to openly criticize staff or express dissatisfaction in interviews, for fear of antagonizing care providers and receiving worse service in the future.

As no approach is without flaws, Newman and Benz (1998) suggested that qualitative and quantitative methods should be seen as an interactive continuum instead of separate scientific absolutes. Each addresses different aspects. Quantitative measures examine the extent of a phenomenon, whereas qualitative measures explore its nature. Depending on the question that researchers and clinicians wish to answer, they should carefully choose the most appropriate methodological approach and be aware of how this may influence their findings. In addition, more mixed-methods studies are needed to examine these differences between quantitative and qualitative end-of-life findings.

Timing of Preference Assessments – When to ask?

Another methodological question concerns the timing of preference assessments. Often, in palliative care research, non-terminal or healthy, elderly respondents are presented with hypothetical scenarios that have little in common with their current situation and are asked to foresee their end-of-life wishes for some distant future. These long-range predictions are problematic. On a theoretical level, Kahneman and Tversky argued in their Prospect Theory (1979) that the further away something is from our current point of reference, the harder it is to make accurate predictions. Wilson and Gilbert (2005) further highlighted that people tend to overestimate the impact that future events will have and underestimate how quickly they will cope with a new situation. Loewenstein (2005) added that we tend to project our current

thoughts, feelings and preferences onto ourselves in the future. This intrapersonal projection poses a particular problem when patients are asked about their end-of-life wishes when they are nowhere near the end of life.

For example, in a population health survey, Foreman, Hunt, Luke, and Roder (2006) asked 2,652 South Australians where they wanted to die if they had a terminal illness like cancer. They found that 70% wished to die at home, 19% preferred hospital, 10% hospice and 1% favoured nursing homes. This has since been repeatedly cited under the mantra that most people want to die at home, neglecting that this study reflects the views of mainly young to middle-aged, healthy respondents. These findings cannot (and should not) be generalized to a dying population. In their sample, 59% were under 50 years of age, and only 21% reported poor physical health. Foreman et al. (2006) acknowledged that older respondents and people with poorer health were less likely to favour home, arguably because they understand the realities of home care better than healthy people. Other studies have shown that preferences often change as the illness progresses leading to a different place of death than initially favoured (Barclay & Arthur, 2008; Gerrard et al., 2011; Higginson & Sen-Gupta, 2000; Townsend et al., 1990). To identify true end-of-life preferences, research therefore needs to include people who are actually near the end of life. Using predictions of healthy elderly participants instead can be seen as measuring preferences too early.

In contrast, end-of-life views are also often assessed too late when researchers use post-death interviews with bereaved caregivers to identify patients' pre-death preferences. These assessments are likely to be biased. Carers may try, in retrospect, to make sense of what happened and justify their decisions. The effects of coping mechanisms, post-decisional rationalization (Wilson & Gilbert, 2005) and hindsight biases (Hoffrage & Pohl, 2003) can influence assessments of past events. For example, when asked about their own and their patient's initial preferences for place of death, bereaved caregivers may (unconsciously) alter their response in favour of the actual place of death. Since the reliability of retrospective

assessments is questionable, end-of-life preferences should be captured prospectively and, if at all possible, close to the end of life.

Sources of Preference Assessments – Who to ask?

The final question when assessing location preferences concerns who to ask. The focus of medical practice and palliative care research is often on the patients' views with less regard to the wishes of the families. Informal caregivers serve as proxies for patients' preferences but are rarely asked about their own wishes. In a review of 129 quantitative studies on home-based caregiving, Stajduhar et al. (2010) criticized that many studies do not distinguish between patients' and carers' preferences, describing them as if they were similar. However, different respondents may have different reference points and hence arrive at entirely different decisions (Kahneman & Tversky, 1979). Since people often have difficulties disregarding their current feelings when predicting their own preferences for the future (intrapersonal projection), they consequently mispredict the wishes of others even more so (interpersonal projection) (Loewenstein, 2005). Studies of surrogate decision-making suggest that carers' assessments are strongly influenced by their own wishes rather than those of the patient (Fagerlin, Ditto, Danks, & Houts, 2001; McPherson, Wilson, Lobchuk, & Brajtman, 2008; Sulmasy, Terry, & Miller, 1998). Cronbach (1955) called this "assumed similarity" (p.177), the tendency to view others as similar to oneself. This bias may also apply to location preferences when caregivers project their own wishes for a place of care or place of death onto their patient. Therefore, researchers and clinicians need to acknowledge patients and carers as two separate entities with different perspectives, preferences and needs.

Implications and Conclusion

In summary, studies addressing where people want to spend their last days differ in the precision, methods, timing and sources of preference assessments and these discrepancies influence their findings. Based on the considerations presented, four suggestions for future research and clinical practice can be made: firstly, we need to be clear in the way we ask care recipients about their views and avoid language that confuses place of care with place of death. Secondly, we must be aware that the methods we use to assess preferences can directly affect the responses we receive. If quantitative measures are used, they should be kept short to minimize participant burden. Yet, overall, qualitative measures are preferable due to the depth and richness of their findings. Mixed methods are of particular interest to compare similarities and differences of both approaches. Thirdly, the timing of preference assessments is essential. The reliability of long-range predictions is just as questionable as the accuracy of retrospective assessments. If we are interested in people's end-of-life preferences, we must ask people who are actually at the end of life. Finally, we must be aware that surrogates do not always provide reliable information on the patients' behalf. Hence, views of patients and caregivers should be assessed separately instead of assuming that they are similar.

Carefully considering these four suggestions will improve the quality of preference assessments in future palliative care studies and medical practice. Only when we are able to accurately identify people's preferences, can we begin to meet the needs of dying patients. These steps are therefore essential to provide better and more efficient end-of-life care in the future.

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