Patients' Choices of the Place of Their Death: A Complex, Culturally and Socially Charged Issue

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The article of Drs. Papke and Koch [1] in this issue of ONKOLOGIE raises many important questions and also stimulates our own existential reflection on how to define 'place of death'. Perhaps, we should start by asking why the subject is even worth discussing. What are the essential and philosophical meanings of 'place of death'? Why is it that, in the 21st century, this issue seems to be framed with the assumption that the question is new – almost as if no society in the past had addressed death as a clearly defined family issue?

It had already been pointed out in the 1970s that we are in an era where medicine is an institution of social control dealing with a wide spectrum of different matters that range from birth to place of death [2, 3]. A recent systematic review examined whether and how 'home' is a 'place of death' [4]. In analyzing Papke and Koch's conclusions that rural people tend to make the choice to die at home, we are faced with the question of what is home [1]. Is it a physical place or rather a 'familiarity', the presence of loved ones, normal life or perhaps the postponement of being confronted with death? Is this why people prefer to die at home?

Data from the WHO concerning palliative care showed that most people in the UK, US, Germany, Switzerland and France died in hospitals [5]. Why, then, is there such a discrepancy between patients' preferences and reality? Unfortunately, no study – including the one in this issue of ONKOLOGIE – provides us with a conclusive answer. Nevertheless, there is evidence for what can be referred to as the 'complexity variables' that influence decisions concerning place of death [4]. These variables include type of diagnosis, timing of palliative care, individual factors, social support and caregiver preferences.

A small pilot study examined the complex and conflicting decisions that women with end-stage cancer face concerning where to die [6]. Is gender a determinant factor in the debate on place-of-death preferences? Papke and Koch describe possible reasons for the differences between the choices of

women with breast cancer during the periods 1997–2002 and 2002–2003, with particular emphasis on the role of economic factors [1]. However, the reasons for this temporal variability are likely to be much more complex. Issues such as the sociological status of women embedded in a large social network, the role of religion and belief systems, and cultural and generational factors affecting the traditional family structure could be conceived as the rationale for a particular decision at the end-of-life stage [7–10].

An analysis of several randomized trials evaluating different home-based palliative programs found that palliative care interventions, such as general practitioner support of patients with end-stage cancer, enable more patients to die at home [11]. Nevertheless, 'dying at home' was only one element that patients considered in the complex realm of what constitutes a 'good' death.

Unlike Papke and Koch, other authors have preferred to use a dyadic approach to decision-making in examining place-of-death preferences of 41 terminally ill cancer patients and 18 of their informal caregivers [12]. One study design involved longitudinal, in-depth, qualitative interviews of patients and relatives in the UK; 13 factors were identified and classified into 4 thematic domains: informal care resources, physical care of the body, experiences of services and existential perspectives [12]. This study revealed a much stronger preference for death in a hospice than at home or in a general hospital.

In view of the different, and at times conflicting, results of the scanty literature on the subject, we may wonder whether and how is it possible to make a fair and objective evaluation of a complex, culturally and socially charged issue such as choosing one's place of death. Patients' choices are, in fact, related to the interplay of many variables, which include the individual relationship between the patient and his or her professional and family caregivers, and the subjective decision-making style of each patient and caregiver.

Cultural and generational differences also play a fundamental role, as elderly patients have been traditionally part of large family units, where care giving responsibilities were and still are effectively shared among all members [13]. To this effect, Papke and Koch mention the ‘increased likelihood of a home death in rural areas ... explained by the continued existence of the traditionally larger family unit...’ [1]. However, the traditional rural area may have now become a place of high social mobility, where the younger generation is being drawn away from traditional norms of large and close-knit families towards a more isolated, vulnerable urban setting. Thus, the preference to die at home may be due to the presence or absence of financial constrictions, the individual patient’s attachment to familiar surroundings, and the possible

apprehension about an unfamiliar hospital setting. Patients may wish to die at home and yet be unable to do so because home-care models are still underdeveloped and family caregivers do not find sufficient practical and emotional support [14]. Patients and caregivers whose needs are met either in a home, hospital or hospice setting may make different individual choices about where to die, as opposed to ‘socially determined’ choices that apply to cohorts.

These and other aspects involved in patients’ choice of the place of death need to be further explored within specific cultural contexts, as well as in cross-cultural studies. The present work by Papke and Koch provides a window through which we can start exploring this complex subject embedded in ethical, social and cultural diversity.

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