Is home always the best and preferred place of death?

The current orthodoxy is that home is the best and preferred place of death for most people. Kristian Pollock questions these assumptions and calls for greater attention to improving the experience of dying in hospital and elsewhere.

Public surveys, particularly among people who are young and healthy, may not accurately predict how individuals will feel when eventually confronted with their impending death. Notably, recent surveys indicate that although home may be selected as the preferred location, the place of death is not itself a great priority. Survey responses rarely give an indication of how respondents anticipate or visualise their death, or what they imagine “dying at home” entails: failing to wake from sleep one day, gently fading out in front of a favourite television show, keeling over in an instant from a catastrophic heart attack, or a process of prolonged frailty and dwindling and the distress of increasing incapacity and dependency? We know little about public understanding or attitudes to death and dying; how this is envisaged, or the effect of complex contextual factors in influencing preferences.

However, there is evidence that people often hope for a quick and unexpected—and certainly a pain free—death. The desire to die at home tends to decrease with age and failing health and to be weaker among patients with conditions other than cancer. Carers are more likely than patients to opt for death away from home, and in retrospective accounts they often consider hospital to have been an appropriate place of death.

An unreflective focus on place as the determining factor of a good death distracts attention from the experience of dying. Just because a death occurred at home does not mean that it was good. The person may have been alone, inadequately supported, in pain, distressed, and fearful. Idealised accounts of “the good death” at home often do not recognise the reality of intractable pain and discomfort experienced by some dying patients and, for a substantial number, the sheer hard work of dying. The effort to keep death at home threatens to over ride consideration of the struggle that may be involved for family carers or the adverse effects of social and economic disadvantage.

Patients repeatedly express a desire not to impose a “burden” on their families and a perceived advantage of hospital is that professional input can relieve the strain. Social engagement—a core value of dying patients—and their personal integrity may be maintained more easily in institutions where staff take over care of “dirty work.”

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suffering and death and the contamination of place and memory that may be a legacy of death at home.10 32 34

Constructing choice in end of life care

The current marriage of palliative care with consumerist ideologies of patient choice promotes the view that the place, and even manner, of death and dying is largely a matter of volition. This deflects attention from the many more substantive factors constraining options, including those relating to availability of resources, the quality and availability of palliative care, the nature of the illness (particularly if not cancer), the severity and management of symptoms, the adequacy of support at home, socioeconomic circumstances, and the environment of care.37 38 We might ask if the notion of “choice” applies to death: most people would prefer, presumably, to be not ill, not old, not dying. We know little about how patients value choice or, indeed, if they perceive themselves to be exercising choice in relation to their options for death and dying.39 41

National campaigns promote a good death as an entitlement: a matter of choice and judicious forward planning (www.dyingmatters.org). But patients often have a more cautious and circumspect approach, suggesting a pragmatic and more realistic appraisal of uncertainty, as well as apprehension, about how they will respond to the unfathomable experience of dying.10 42 43 Some patients may be undecided or uncertain and wish to relinquish the responsibility of “choice” to others.30 34 In relation to intrinsically tragic outcomes, the obligation to choose may be experienced as risk and burden.40 44 45 A stated preference for home may constitute a positive choice. Alternatively, it may be regarded as the least bad option.24 25

Conclusion

Focusing on place of death as the key indicator of quality in end of life care distracts attention from the experience of dying for patients and their families.10 28 Evidence suggests that place of death is not the over-riding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important.4 11 18 36 Much greater understanding of patient and public experience and attitudes to death and dying is needed, including where this should occur. When patients wish to die at home, every effort should be made to achieve this outcome. However, until resources are in place to adequately and equitably support home deaths, the current promotion of patient choice risks raising expectations that are not realised.46 There are many reasons why patients may not wish to die at home. Death at home is not necessarily good, and just because a patient did not die at home does not necessarily mean their death occurred in the wrong place. It is important to recognise and accommodate the diversity of patient preferences for place of death, especially in the context of a cultural heterogeneity that is rarely researched or recognised.35 47

When home death becomes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences.46 Patients may be offered choice but be expected to “choose wisely.”46 Rather than reflecting prior and clearly articulated positions, patients’ recorded preferences may become co-constructed artefacts of a discussion shaped by professional perspectives and agendas.27 46 However well intentioned, these are inevitably influenced by pressure to achieve performance indicators for quality of care.27 46 Normalising home as the best and natural place to die promotes a sense of guilt and failure if death occurs elsewhere.46 The cultural script about death and dying risks being rewritten to promote ostensive choice as de facto obligation. Given the projected increase in institutional deaths, the hospital needs to be reinvented as a viable alternative and place of excellent care for dying patients and their families.

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