

## ANALYSIS



## 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

Kristian Pollock *principal research fellow*

Nottingham University, School of Health Sciences, Queen's Medical Centre, Nottingham NG7 2HA, UK

Place of death has become a key indicator of the quality of end of life care,<sup>1 2</sup> underpinned by the conviction that most people would prefer to die at home.<sup>3 4</sup> The institutional environment of acute hospital wards is considered an inappropriate and undesirable place in which to die,<sup>5 6</sup> and there are concerns about poor quality of care.<sup>7-9</sup> The need to reduce costs is a further incentive for reducing deaths in hospital.<sup>6 10 11</sup> However, the evidence on patients' preferences is unclear and conflicting. Regardless of preference, hospital will remain the most common place of death for the foreseeable future.<sup>6 12</sup> Far from neglecting and disregarding the hospital as a site of terminal care, much greater thought and adequate resources must be directed to enabling hospitals to provide excellent support for dying patients and their families.

### Is place of death a public priority?

Public surveys commonly report that around two thirds of respondents express a preference to die at home.<sup>3 6 13-15</sup> However, there is considerable variation between studies. A substantial number of people do not specify a preference,<sup>16</sup> and there is rarely an option for "it depends" or "does not matter."<sup>17</sup> The context and framing of the questions will shape the nature of responses, and studies vary in their design and quality.<sup>3</sup>

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.<sup>10</sup>

Notably, recent surveys indicate that although home may be selected as the preferred location, the place of death is not itself a great priority.<sup>10 18</sup> 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.<sup>19</sup> However, there is evidence that people

often hope for a quick and unexpected—and certainly a pain free—death.<sup>13 20-22</sup>

### What matters most to patients?

Patient surveys also find that home is the most commonly expressed option,<sup>23</sup> although often respondents do not record a preference.<sup>8 15</sup> It is widely stated that many more people die in hospital than wish to do so. However, a recent systematic review concludes that the evidence for this assertion is not as strong as previously thought, particularly if changes in preference throughout an illness are recorded.<sup>3</sup> Preferences for place of care are rarely clearly differentiated from place of death.<sup>15</sup> When they are, preference for care at home is greater than for death at home.<sup>6 10 13 24</sup>

As with the evidence from public surveys, it seems that although patients may specify home as their preferred place, location may not be a high priority,<sup>15</sup> especially in comparison to freedom from distress and pain.<sup>4 10 18 22</sup> Qualitative evidence indicates that patient attitudes to place of death are complex, uncertain, shifting, and pragmatic.<sup>13 15 20 25-27</sup> The desire to die at home tends to decrease with age and failing health<sup>3 10 13 22</sup> and to be weaker among patients with conditions other than cancer.<sup>13 27</sup> 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.<sup>3 17 24</sup>

An unreflective focus on place as the determining factor of a good death distracts attention from the experience of dying.<sup>10 28</sup> 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.<sup>10 25 26</sup> 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.<sup>29-31</sup> 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.<sup>6</sup>

Patients repeatedly express a desire not to impose a “burden” on their families,<sup>6 10 13 20 25 30 32 33</sup> and a perceived advantage of hospital is that professional input can relieve the strain.<sup>25 30 32</sup> 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.”<sup>26 32</sup>

The hospital may be preferred as a place of safety and effective control of symptoms, especially when pain and distress are difficult to overcome.<sup>13 17 34 35</sup> Dying in pain is consistently reported to be the greatest concern of patients and the public.<sup>4 9 10 36</sup> However, some expect or find that pain is less well controlled at home.<sup>8 10</sup>

The value and emotional importance of home as a safe and private space may be degraded by its annexation as a site of hospital outreach and the invasive influx of equipment and staff that dying at home requires.<sup>6 26</sup> Patients and family members may have concerns about the witnessing of suffering and death and the contamination of place and memory that may be a legacy of death at home.<sup>30 32-34</sup>

## 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.<sup>37 38</sup> 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.<sup>39-41</sup>

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.<sup>30 42 43</sup> Some patients may be undecided or uncertain and wish to relinquish the responsibility of “choice” to others.<sup>20 34</sup> In relation to intrinsically tragic outcomes, the obligation to choose may be experienced as risk and burden.<sup>40 44 45</sup> A stated preference for home may constitute a positive choice. Alternatively, it may be regarded as the least bad option.<sup>24 25</sup>

## 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.<sup>10 28</sup> 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.<sup>4 13 18 36</sup> 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.<sup>46</sup> 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.<sup>32 47</sup>

When home death becomes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences.<sup>34</sup> Patients may be offered choice but be expected to “choose wisely.”<sup>(34)</sup> 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.<sup>27 46</sup> However well intentioned, these are inevitably influenced by pressure to achieve performance indicators for quality of care.<sup>27 46</sup> Normalising home as the best and natural place to die promotes a sense of guilt and failure if death occurs elsewhere.<sup>30</sup> 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.

Contributor and sources: KP has a background in social and medical anthropology and has carried out qualitative research in a wide range of healthcare settings. This article has developed from her involvement in investigation of public attitudes to death and dying, the care of older patients dying on acute hospital wards, and the initiation of advance care planning in community care settings.

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**Key messages**

Current assumptions that home is the best and preferred place of death oversimplify patient and public attitudes and preferences for death and dying

Preoccupation with dying at home as an indicator of a good death deflects attention from improving the quality of care available in other places

It is more important to focus on the experience of dying than the place of death

Hospitals will remain the place where most people die and need to provide excellent end of life care

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