

Whose Business is Dying?

Death, the Home and Palliative Care

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—BACKGROUND

Support and care of people at the end of their lives, in some form or other, is present in all societies. What is referred to today as *palliative care* represents a particular response to death and dying set in specific historical and cultural contexts.¹ The modern hospice movement originally emerged, at least in part, as a response to the perceived neglect of dying people by the dominant biomedical model of health care in parts of the Western world during the post-war period.² While it was acknowledged that the biomedical approach enabled the development of proficiency in the cure of disease and prolongation of life, some argued modern medicine had lost its human face.³ Medical progress in the twentieth century ‘transformed the experience of dying from a part of daily life to a highly technological event’.⁴ Death left home, as it were; its stewardship increasingly relinquished by families to charitable institutions, to newly emerging acute hospitals or simply left to chance. As a consequence, the home—the domestic space normally the sphere of family, care

and comfort—has increasingly been replaced by institutional spaces as the most fitting scenes for death to occur.

The biomedical model has been criticised for removing the sick or dying person from their social context.⁵ Diagnoses and treatments increasingly failed to correspond to the day-to-day reality of health and illness experienced by ‘ordinary people’.⁶ Dying and death is not considered solely a health care event, but is seen rather as a societal concern affecting individuals and their personal, interpersonal and social contexts, as well as whole communities.⁷ This sentiment has been eloquently captured:

The experiences of serious illness, dying, caregiving, grieving and death cannot be understood within a medical framework alone. These events are personal, but also fundamentally communal. Medical care and health services constitute essential components of a community’s response, but not its entirety.⁸

Yet, despite its origins as ‘a small rebellion against the way dying people were cared for’, palliative care continues to exhibit many of the paternalistic practices of mainstream health care that its forebears were resisting.⁹ These practices, while well intentioned and often effective, find their origins in a sense of ‘ownership’ of the business of dying. But the clinical expertise of palliative care practitioners in the business of dying does not equate with ownership. The benign—but enduring—paternalism of palliative care service provision remains a philosophical and structural barrier to a paradigmatic shift towards a more complete understanding of the business of dying. Nascent attempts to promote community engagement in end of life issues are evident in the interface between palliative care and public health but dying remains, for the most part, the remit of health care services. As such, the business of dying is incompletely attended. I argue here for a need to reappraise the business of dying, and for the home to be seen as a fitting death scene.

—THE CUSTODY OF CARE

The modern hospice movement sought to restore a ‘holistic approach to patient care, the family as the focus of care, and importance of multidisciplinary collaboration on a day to day basis’.¹⁰ It reclaimed dying through localised

community action, with the momentum for the development of services often led by individual clinicians and idiosyncratic funding decisions.¹¹ This unregulated and rapid proliferation of palliative care services in the Australian setting has been described thus:

The growth of specialist palliative care services for patients has been mostly unplanned and uncoordinated by Health Authorities. Development has been largely in response to local pressure, enthusiasm, and fund-raising activity, and remained mostly within the charitable, independent sector.¹²

As a result, it seemed inevitable that conventional palliative care services would be integrated into the mainstream. By the end of the 1990s, evidence of the extent of palliative care's mainstreaming was reflected in Faull's statement that 'palliative care is not an alternative to other care but is a complementary and vital part of total patient management'.¹³ This was a destination perhaps not envisaged by the pioneers of the modern hospice movement, and some authors expressed concern that such integration represented a threat to the founding principles of hospice and palliative care through its routinisation and medicalisation.¹⁴ Conversely, Clark warned the palliative care discipline not to self-destruct through protective custody of specialist knowledge, and to instead become more involved in the resourcing of mainstream services.¹⁵ One cost of this mainstreaming of palliative care services, it is suggested, is the progressive abandonment of the social context of dying people, increasing instead 'the emphasis on physical care' while 'simultaneously de-emphasizing psychological, social and spiritual care'.¹⁶ Kellehear and others have proposed that the repositioning of palliative care services within mainstream health care systems has increased a focus on illness and disease at the expense of health and wellbeing. It has also been suggested that contemporary models of palliative care are profoundly paternalistic and devaluing, and therefore fundamentally flawed.¹⁷

The mainstreaming of palliative care retained a focus upon models of service provision, and although providing some important clinical benefits to 'users', demonstrated that many contemporary conventional models of palliative care do not adequately locate death and dying in the social context of people's lives.¹⁸ Ironically, this is the criticism made of mainstream health care from which the

modern hospice movement originally emerged in reaction to. As claimants to the custody of the care of dying people, has palliative care fallen short?

—THE 'USERS' OF PALLIATIVE CARE

Paradoxically, it has been pointed out that while the modern hospice movement has always held local activism—and therefore, to some extent, community ownership—in high esteem, the systemisation of hospice into the health care specialty now called 'palliative care' had again disenfranchised the very groups the palliative care professional community must rely on for its survival. Small stated that 'user voices were squeezed out, indeed health professionals were given more authority to define users' involvement and there was a tendency to conflate user involvement and public participation'. This assertion directly confronts the modern hospice movement's own view of its role in the empowerment of 'users'. Small went on to explore the problematic nature of 'user' involvement in palliative care, arguing that only consumers of palliative care can truly assess what constitutes a good death, and therefore what good palliative care might resemble.¹⁹

Firstly, he cautioned against the hybridisation of consumers of palliative care as some kind of homogenous group, despite their very different needs and priorities, compounding the existing generalisations made on the basis of ethnicity, family roles and conceptualisations of suffering. With few exceptions, a good death has largely been measured by nurses' perceptions of patients' and families' acceptance of the death and the degree of peace with which it was met.²⁰ One of these exceptions is found in Kellehear's early interviews with one hundred dying people, where the core elements of a good death were identified as an awareness of dying, preparations for death, capitulation of roles and responsibilities, and making goodbyes with others.²¹ In their critique of his study, Hart, Sainsbury and Short noted his emphasis upon:

the active and critical role that dying people played in the social management of their dying as they engaged in separations and made preparations for the end of their lives. [A good death] is a set of culturally sanctioned and prescribed behaviours set in motion by the dying, through which their death is made more meaningful for all concerned...²²

Such a socially approved form of dying raises the question whether ‘the choices of dying people [are] increased or constrained by the ideology of the good death?’²³ If the latter is true, then the apparent disenfranchisement of dying people within today’s mainstreamed palliative care services is cause for concern. In Australia, McNamara, Waddell and Colvin have explored whether the gold standard of the ‘good death’ was congruent with the fiscal, administrative and organisational priorities of palliative care facilities.²⁴ The concern of palliative care providers for the achievement of a good death now presents them with one of their greatest contemporary challenges—can the palliative care profession defend its claim of patient-centred holistic care and respond to changing consumer expectations of how dying can take place? If a palliative care service is to be truly responsive to its ‘users’ (as part of its patient-centred claim), it must be prepared to challenge the common assumptions of what a good death might be.

Second, Small suggested that the very involvement of ‘users’ in palliative care can, paradoxically, inhibit opposition to the *status quo*.²⁵ Evidence of ‘user’ involvement can be used to justify narrow definitions of need that again fail to address the complexity of dying and the human experience of suffering that often accompanies it. In a related commentary, Clark and Seymour warned of the dangers of uncritically pigeonholing individuals as ‘clients’, ‘patients’, or ‘informal carers’, labels that denote ‘a mono-dimensional perspective which is capable of seeing human beings only in relation to the formal organisations of health and social care’.²⁶ That is to say, viewing the recipients of palliative care simply as consumers of services takes those services as the reference point from which the persons’ illnesses are understood, and might risk losing sight of the social context of people’s daily lives.

—HEALTH PROMOTING PALLIATIVE CARE

A health promoting approach to palliative care is one that claims to provide a vehicle for ‘user’ involvement in core issues relating to death and dying, and the provision of responsive health care. A defining feature of both palliative care and health promotion is their participatory nature and this represents a significant area of conceptual overlap between the two fields.²⁷ The imperative to develop health-promotion services using input from potential consumers of those services is

reflected in the historical origins of the modern hospice movement and health promotion.²⁸ While other researchers had presented the notion of utilising health promotion in the practice of palliative care prior to 1999, Kellehear's book *Health Promoting Palliative Care* was the first substantial attempt to theoretically and systematically integrate these two parallel but distinct fields. Of course, the public health discipline has explored in detail the relationship between human health and well-being, and social and environmental factors.²⁹ Contemporary understandings of health recognise the impact of disease, illness and health-related issues upon all aspects of human existence and, notably, the role of individuals, communities and societies in determining their own health outcomes.³⁰ Health-promoting palliative care is a social model based on a conceptual perspective that promotes optimal health even in the presence of incurable disease. It utilises palliative care philosophy to inform the development of organisational mission, values and strategic directions. The World Health Organization's (WHO) *Ottawa Charter for Health Promotion* also supplies parameters for determining the scope of goals and objectives for health promoting palliative care.³¹

Kellehear's premise was 'if health is everyone's responsibility then it is also the responsibility of those living with a life-threatening or terminal illness as well as those who care for them'.³² He explored the core concerns of palliative care, citing the WHO definition of palliative care, the key action areas of the *Ottawa Charter*, and the foundational work of Saunders and others, emphasising the centrality of holism as a response to the multidimensional nature of care at the end of life.³³ Critical of the discrepancy between rhetoric and reality, Kellehear cited the overemphasis on physical—and, to a lesser extent, psychological—symptomatology at the expense of the social and spiritual domains, referring to the concerns expressed by Kearney.³⁴ Subsequently, in *Compassionate Cities*, Kellehear again observed the historical transference of responsibility for dying from the community to the health care professions, with many of the conceptual and practice parameters determined by clinical services rather than by consumers of those services.³⁵ Moreover, he suggested that the palliative care profession continues to focus upon individualised responses to need rather than social change, writing:

Dying, death and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour. This

reinforces the view that clinical rather than community skills should take priority in palliative care education and training.³⁶

Others had also undertaken substantial work towards facilitating a transition from end of life care that focused upon the clinical care of individuals, to a community—that is, *social*—approach.³⁷ These authors saw the engagement of broader social networks in end of life issues as having a reciprocal effect—the community members' perspectives of death and dying informed their engagement, while their engagement reshaped their perspectives. They argued that connecting health to the community, providing information and establishing partnerships will raise death awareness, empowering participants individually and collectively so that the community is equipped to debate issues at the end of life as a sound basis for end of life care.

Although the prominence of consumer feedback in palliative care services has diminished as such services have become mainstream, it is again being viewed as essential to informing the nature of end of life support and implementing possible changes to practice.³⁸ Participation in the health promotion tradition, however, is not limited to simply providing feedback on, or satisfaction with, service provision, although this is clearly an important consideration. Implementing a health-promoting palliative care model in an organisation clearly requires strategies for the involvement of community members beyond conventional palliative care practices such as volunteering and fundraising. A social model of health care requires an organisation to embrace the contribution of community members in all aspects of their strategic activity. Health promotion advocates the participation of the community (including actual and potential consumers) 'in all stages of planning, implementing and evaluating policies and services that impact on health'.³⁹ It has been proposed that effective consumer participation in a health promoting palliative care organisation should stand up to scrutiny against the key criteria in the health promotion field, as well as in the ways proposed for health promoting palliative care.⁴⁰ These criteria include:

- Clear and formalised organisational commitment to community participation
- Organisational structures and processes that promote ongoing involvement of consumers

- Acknowledgement of potentially divergent agendas of community and organisation
- Commitment of resources to support participation
- Use of accessible, everyday language that includes non-health professionals
- Training for staff, management and community members in values-clarification and development of shared goals
- Appropriate evaluation of the effectiveness of community participation.⁴¹

Rao and colleagues further asserted the need for the concrete inclusion of a public health foundation in palliative care service planning.⁴² In one study of public health priorities for end of life initiatives, they identified nine clusters of public health activity that were directly relevant to the provision of palliative care. Of these, five were identified by the palliative care professions as most feasible:

- Public education, including death education
- Patient, family and caregiver education
- Research, epidemiology and evaluation
- Professional education
- Policy and planning

For example, in the public education cluster, it is advised to make use of strategies to raise public awareness of the issues of death and dying and palliative care, increase the use of advanced health directives, integrate end of life issues into chronic disease educational materials, and operate some form of information clearing house for end of life issues.

These activities differ from conventional palliative care insofar as they propose approaches to end of life care that are based in community participation in the discourse and activities of dying and death, rather than simply the provision of health care services specific to dying people. This paradigmatic shift entails the engagement of the so-called 'user' of palliative care in the shaping of care. Clearly, these strategies demonstrate contemporary attempts to reverse the disenfranchisement of the 'users' of palliative care described above. However, they have not been integrated comprehensively in most countries with formalised

systems of care of the dying, signifying the very dynamic state of the ownership of the business of dying.

—HOME AS A PLACE OF DYING AND DEATH

Home is a place of care where the tension between the paternalism of mainstream palliative care and a social understanding of end of life care is present. The process of dying at home brings this state of play into sharp focus. Away from institutional places of care, issues of ownership, compliance and communal responsibility are heightened. As a community palliative care clinician, the manner of my engagement with recipients of care was changed precisely because I was entering the home of another, rather than an institutional place of care. I 'owned' my clinical expertise and proximity to issues of death and dying, but was nevertheless a guest in the home, a space 'owned' by the recipient of care, their family and their community. The negotiation of the care-giving relationship between me as the 'provider' and the patient as 'user' was inadequately served by relying on conventional notions of service provision in a non-institutional setting of care. Rather, an acknowledgement of the home as a place of the person's dying was essential in establishing a relationship that was both therapeutic and interpersonal. This complex link between the clinician and the dying person has been described in terms of a 'therapeutic relationship', where the expertise of the clinical and the lived experience of the dying person are equal components in this transaction.⁴³ This permits a non-paternalistic, interpersonal exchange between the clinician and the dying person in this place, and indeed, elsewhere in settings of care.

Home as a place of dying is, of course, not a new notion, as the brief tracing of the modern hospice movement above demonstrates. Indeed, palliative care's evolution has consistently included consideration of the interface between home, hospice and hospital, and this continues today. In an alternative approach to established thinking about palliative care, Sinclair criticises the palliative care models based upon this 'triangle of care' for maintaining the institutional agenda, rather than integrating the home as a distinct place of care.⁴⁴ This assertion carries some weight when one considers that the 'triangle' is driven by service providers and that any attempt to regulate the home as a place of care is problematic. The euphemistic 'hospital in the home' is an emerging approach to home-based care that

demonstrates this dominance of institutionalised models in the community sector. Whilst not readily taken up by community-based palliative care services, the broader reintegration of end of life care into mainstream health care described above makes these services susceptible to institutional models of care.

The converse view to this dominance of the institutional agenda is, of course, to reorient thinking about end of life care from the social perspective. The *starting point* for better understanding the home as a place of dying lies in the ordinariness of living, the ordinariness of belonging to communities. From the dying person's perspective, home is normal—hospitals, let alone hospices, are somehow 'other' for most people. The early work of researchers such as Kübler-Ross and Glaser and Strauss, later criticised for their considerable methodological limitations, pioneered the placement of the person in their social context—including home—as the starting point for discussions of the dying experience.⁴⁵ Viewed from this perspective the scene of death is characterised by normality, domesticity and familiarity. Each of these features work to break down the alien environment of the institutional death scene and challenges the health care professional to think differently about their place in this death scene. Health services providing care to dying people in their homes are present at an interface where the palliative care profession is confronted with the irony of relinquishing its 'ownership' of the business of dying while leading communities to reclaim their principal role in the business of dying. The very services possessing the expertise to lead this shift in control are the same services that would be required to cede that control.

The 'user' of community based palliative care services need not be the passive recipient of institutional services somehow transferred from hospital to home. If this were true, the social contract between the home dweller and the visiting health care professional would not differ in the home from that between the hospitalised 'patient' and the health care professionals. The 'user' holds the status of the starting point for considering the types of responses to their illness that are relevant and sought. This would usually include the accessing of health care services; however, the mobilisation of social networks—both professional and vernacular—form the broader context within which this health care is provided. Dying is conceptualised as a communal event beyond the remit of health care services generally, and palliative care services specifically. This provides some

conceptual foundations for the application of health promotion to palliative care described above.

This is not to suggest that home is somehow an idealised place of care for dying people:

People who are dying, while remaining in their community in their own homes, live with the good and the bad encountered among people living in any normal community. People may experience stimulation, comfort, companionship and pleasure from others, as well as ignorance, rejection and patronisation.⁴⁶

What home is, however, is *normal*. For the experience of dying, which is described here as a communal event, not just a health care event, this is an appropriate premise upon which to conceptualise home as a place of dying.

It is clear that for dying people, home is a preferred place of dying. But there is a discrepancy between the stated desire to remain at home while dying (up to and including death) and the number of people who actually do die at home. In the United Kingdom, it is estimated that fewer than twenty per cent of terminally ill people die at home despite a large majority expressing a preference for it; indeed, the trajectory of illness progression demonstrates that most terminally ill people spend most of their time during their illness at home, but are transferred in the final days to a care facility.⁴⁷ This pattern is replicated elsewhere in the developed world. In a Canadian study, the figure drops to sixteen per cent for urban dwellers and fifteen per cent for rural dwellers who die at home.⁴⁸ Regardless of the perceived *normality* of home, perceptions of its appropriateness as a place of dying vary according to individual, familial, community and cultural expectations. Individual preferences and family members' availability to provide care are widely variable; the capacity of local communities to support their dying members differs. The expectations of ethnic groups and educated consumers of health care, along with the professionalisation of care of the dying, are cultural influences on this choice.

So what makes dying at home happen? In a systematic review of fifty-eight studies of influences upon achieving death at home, a complex, multifaceted configuration of factors emerged.⁴⁹ The review identified three key areas influencing whether death would occur at home: first, factors relating to illness, such as long disease trajectory and low functional states; second, individual factors including

optimal social conditions and an express wish to die at home; third, the utilisation of home care services, rural dwelling, being married, living with extended family support, having agreement between the patient and carer about dying at home and historical trends. These findings were partially reiterated in another Canadian study that identified two key determinants in achieving a home death: the express wish to die at home and having a family member providing care and support at home; notably, the capacity of the family to provide support was seen to be enhanced by the provision of comprehensive home-based palliative care services.⁵⁰

Conversely, of course, occupants may view home as an unsuitable death scene. Many terminally ill people clearly delineate between home as a place of *dying* and home as a place of *death*. The transfer of dying people from home to hospital in the final days of life noted above is not necessarily because of a loss of control or ownership over the process of dying; it may, in fact, represent the exercise of that control. It has been estimated that preferences for place of dying and death remain unchanged for about seventy per cent of dying people and their carers.⁵¹ Difficulties arise when these separate preferences do not change simultaneously; the dying person may be fearful of placing an unreasonable burden on their carer, or have concerns about uncontrolled suffering in the final stages of dying outside of institutional care, while the carer may be anxious about their ability to provide adequate care at home, even with the support of palliative care services. In my own experience, I have observed bereaved carers stating that they will 'never go into that room again' or having the bed in which their family member died destroyed, as the thought of it being the location of death at home was too tangible a reminder.

—CONCLUSION

These considerations demonstrate the complex and dynamic nature of the transaction between the dying person, their family, and the palliative care service providers. A non-institutional, non-paternalistic approach is essential to achieving optimal outcomes for the person dying at home. I have contended here that the business of dying is incompletely attended by contemporary palliative care. Is it that past models of care are no longer useful? Are there approaches to the provision of care and support of dying people that capture the advances of the past few decades and combine it with a more complete understanding of the business of dying at

home? Do the attempts to normalise dying at home described above sufficiently emancipate palliative care consumers from the paternalism evident in current models of care? Some authors believe that the paternalism demonstrated in a 'commitment to the medical model from cradle to grave' no longer meets the changed expectations of health care consumers.⁵² In addressing life-threatening illness and end of life care in the context of health promotion in families, it has been suggested that health care consumers face challenges as never before, where new end of life choices are more complex than imagined when the modern hospice movement began.⁵³ With a more highly developed sense that death belongs to community, more empowered, active communities are likely to respond differently to issues of death and dying wherever they are encountered, whether in workplaces, schools, communities or family homes. It can be speculated that a longer-term impact of implementing health-promoting palliative care approaches would change the dynamics of service provision as community members become consumers of palliative care services and demonstrate a greater preparedness for either their dying or their care-giving responsibilities. This remains the subject of further research.

The home setting as a death scene is not, and cannot become, an institutional place of care, fully regulated by expert professionals. The home—in all its varying forms—is a place considered 'normal' by its occupants, where ownership of, and control over, its boundaries rests with those considered as subject to the paternalistic practices of conventional approaches to palliative care. By extension, the networks formed by the linking of these homes and their occupants create a community that 'owns' the business of dying amongst its numbers. A model of palliative care that integrates the principles and practices of health promotion and public health is proposed as one approach to normalising the conceptualisation of dying and the responses of communities to their dying members. Whose business is dying? As home-based care is a death scene where the tension between the paternalism of mainstream palliative care and a social understanding of end of life care meet, it offers the opportunity to reconceptualise dying as the business of individuals, communities and societies, including, but not constrained to, the provision of palliative care.

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—NOTES

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