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Spatial practices and the home as hospice

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DISCUSSION PAPER

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Abstract

The modern hospice movement emerged in the late 1960s largely as a reaction to the way in which death and dying were dealt with in the hospital building. From the early development of the hospice movement, setting was considered to be very important. Hospice buildings were more residential and "homely" than their hospital counterparts. However, with the widespread development of "hospice home-care" programmes in the 1980s, this emphasis on place and setting changed, and along with it the meaning of the term "hospice" has changed. The current claim of the hospice movement is that "hospice" is a philosophy of care not a building or place.

Home is now widely considered to be the best place to die, a place of familiar surroundings and the company of family and friends. The modern preference to die at home relies on traditional models of home, family and community. Dying at home was at one time commonplace and envisioned within the design of the home, and caring was a normal expectation of key family members. In modern society, however, dying is generally not a considered function within the design brief of the home and families may be unable, through economic, geographical or other reasons, to be carers. Thus, for some, home may not be the best place to die and family may not be the best carer. As a result, many people, despite their preference for home, still end up dying in the hospital building. This paper discusses the spatial issues surrounding the concept of home as hospice and questions the universal suitability of the contemporary home as a hospice.

Key Words
Hospice, architecture, spatial practice, home

Introduction

The notion of home as the idyllic place of our childhood, full of memories and life, as French philosopher Gaston Bachelard proposes in *The Poetics of Space*[1], presents a poetic and, perhaps nostalgic, view of home. How people live at home in contemporary society would affect how people might die at home in the future. Living alone through divorce, widowhood or by choice, residing in an apartment building, shared or rented houses or in an aged-care unit, and moving houses, neighbourhoods, suburbs and cities frequently — all these patterns affect how we live, as they affect the notion of "home" and our capacity to die there. The perfect death might be envisioned symptom and pain-free, surrounded by family and friends at home, having lived a long and fruitful life. However, this is not the case for many dying patients.

The movement of death

The place of death and dying has moved from home to hospital, to early "homes for the dying," to hospice and back home again. However, despite this movement and the modern preference to die at home, the hospital continues to be significant as a place of death in contemporary society.

Before the advent of modern medicine and the modern hospital, death tended to be a public affair set on the dramatic stage of a crowded bedroom with the dying person centre stage playing the lead.[2] In the crowded bedroom of the nineteenth century, the dying person was the centre of attention. The transfer of death from the family home to the hospital started in the early twentieth century. Changes in the family structure, increased mobility, and the transfer of health and welfare dependency from family to state saw this trend become widespread by the 1950s. With the promise of elaborate treatments, advances in surgery and the use of major equipment, the hospital gave new hope to patients and their families. However, not all the new treatments worked and death became an

inevitable by-product of this medical advancement. Thus death, once accepted in the home, came to be seen as a "failure" of medicine in the hospital. With failure comes hiding. In *The Hour of Our Death* Philippe Aries describes the hospital's dealings with death as the "invisible death," where the patient, for whom medical science has failed, is removed to a private, or hidden, place.[2]

The modern hospice movement emerged largely as a reaction to the systems and environments of the hospital building and to their dealings with dying. The philosophy of the modern hospice movement was "concerned both with the sophistocated science of our treatments and with the art of our caring, bringing competence alongside compassion".[3] The resurgence of caring for the dying at home emerged in the late 1970s with the commencement of hospice home-care services. The move toward offering a choice or blend of hospice in-patient or home-care services gained popularity in the 1970s and 1980s and was pivotal in the development of the philosophy of the modern hospice movement beyond the bounds of the hospice building. This move changed both the way care was administered and the way the hospice building was used.

Home death

However, despite this move towards the provision of more home-based hospice services, the earlier removal of death from the home to the hospital marked a change in society's familiarity with death. In modern times death has become commonplace in television dramas, even as our contact with death in reality has become unusual. The laying out of the body in an open coffin at home, for instance, is now relatively rare. In contemporary Western cultures, the home is no longer designed to envision death as it was in the past. The Irish Draft Building Regulations, used up to the 1970s, for example, based the dimensions of a staircase on the size of a coffin. So the hospice movement's favouring of home as the best place to die presents new challenges to the design of the modern home, where all traces of death have been removed from its brief and replaced by the optimism of life.

The current preference of the hospice and palliative care movement for dying at home is supported by changing public attitudes to preferences for their place of death. For instance, Ireland's 2004 *Nationwide survey of public attitudes and experiences regarding death and dying* found that 67% of respondents "preferred place of care if dying" was "in your own home" with only 10% choosing "in a hospice" and ironically the same percentage (10%) chose "in a hospital".[4] This favouring of dying at home not only challenges the design of homes but also presents new challenges to the design of in-patient hospice buildings, where admittance is often preferred or restricted to those whose symptoms are too distressing to be attended to at home by family, or where no family are available, able or willing to be part of the care team.

In any case, despite the ideal and preference for dying at home, surrounded by family, the home and its associated spatial practices does not always provide the best arrangements in regard to the dying person's privacy, accessibility, outlook and comfort, just as the family carer may not be able to provide the best nursing care. In 1998 in *Contemporary Hospice Care* Julia Lawton presented an interesting alternative view to the ideal of the home death.[5] Lawton discusses individual patient cases and their preference to be looked after by professional hospice staff within the hospice building rather than at home in order to protect themselves and their family from the embarrassment of their symptoms. It is interesting that in Lawton's findings the idea of "privacy" was perceived to be more available in a hospice than at home, where the patient "felt she could not get enough privacy at home to attend to her personal hygiene". In this case, the dying patient found the symptoms of the particular disease "deeply distressing and embarrassing" and "did not want her family to witness her bodily degradation first hand". Two important ideas are illustrated by this case study. The first is that the place, in this instance the patient's own home, did not allow for patient privacy, as the hospice did, and the second is that the patient's sense of privacy *excluded* her family, but *included* staff, in ways that allowed the patient to be "presented" to the family rather than seen deteriorating by them. This suggests that home is not always the most suitable nor is family necessarily the most suitable carers:

> […] while theoretically the affective dimension of informal care marks it [the home] out as qualitatively superior, in practice this is not necessarily the case. Informal care is an uncommandable, unspecifiable resource that is unevenly distributed.[6]

The reality for many is that care in the patient's or the carer's home is not ideal for various and complicated reasons. The relationship of the patient to carer — son to mother, husband to wife, sister to brother, and so on — the ability of the carer to cope, the patient's (and carer's) fear, and the spatial organisation and practices of the home can all contribute negatively as well as positively to patient and carer well-being. Thus the decision to die at home, in a hospice or a hospital is neither "good" nor "bad" but is highly complex and differs in every individual situation.[7]

In response to the trend in the United Kingdom toward "care in the community" (and also in response to economic issues) there has been a reduction in available bed numbers in many hospices and palliative care units. Limited bed numbers may result, in some cases, in changes to admission policies, with preference given to those with distressing symptoms rather than to respite care or to those who would merely prefer to die in a hospice.[5] Julia Lawton suggests that there is "the marginalisation of patients within the physical space of contemporary hospices" and argues that it is the inability of the body to cope with symptoms of disease or "boundedness of their bodies" that leads to their admittance to the hospice. Lawton goes on to suggest that "the conceptualising a hospice as a 'no place' — i.e., a space within which the taboo processes of bodily deformation and decay are sequestered — allows it to be understood as a central part of contemporary western culture".[5] These factors suggest that the preference and decision to stay at "home" (either the patient or carer's home) or stay in a hospice is often, in fact, not a matter of patient (or carer) choice, but more a decision about what is deemed to be the ideal practice.

Thus in contemporary times, while dying in hospital was often considered a failure of medical sciences, comparably dying in a hospice can also indicate failure — failure of the body to cope with the unmanageable and distressing symptoms or failure of the home or family to cope with dying at home. In many situations the failure may actually be the failure of the home to afford the patient, carer and family the space and associated practices that supports holistic and dignified hospice care. The denial within the hospice philosophy of any emphasis on space highlights a lack of consideration of the complex connection between human needs and spatial practices. The hospice movement's mandate for "dignity and dying" must be read not just in terms of care but as care in conjunction with space and spatial practices. This link is particularly illustrated in Lawton's case study where patient privacy and patient dignity are intrinsically linked to the choice of setting.

The choice of the place to die is based on many complex factors: the level of necessary symptom management; patient anxiety and fear; availability of suitable family carers; and the suitability of the home. While the general preference is to die at home, the contemporary home is often not designed to envision death or dying. Admittance to a palliative care unit or an in-patient hospice building for some, who may be alone, replaces both home and family; for others it may reflect personal choice. Patient dignity and privacy, essential to the hospice philosophy, vary with individual circumstance and are linked to spatial practices. Thus, the consideration of hospice space, whether in a purpose-built hospice, a palliative care unit within a hospital, a nursing home, or at home, is critical to support the patient and family choice. The inclusion of the notion of a "family atmosphere" is critical to presenting the hospice space as a homely community within any setting, not just within the home. While the setting, in the first instance, is called upon to address patient comfort and care, just as important is the ability of the space to address feelings of loneliness, isolation, failure or guilt for both patient and for their family.

The major shift in palliative care toward home-care support services, enabling people to die at home in many cases provides an ideal arrangement. However, the success relies on the presence and ability of family and friends to make this the ideal way to die. The hospice movement preference for care to be given at home using the "dying triad" (of patient, informal carer and hospice professional) is dependant on the social relationship of patient to carer. As a result of this shift, the provision of in-patient hospice services has become limited and results in admittance being often reserved for patients whose family circumstances do not allow or want home-care. This division exposes differences: those that have capable family and suitable homes, and those that do not. The impact of economic factors, both for health departments and for families, also influences the hospice philosophy and practice to move care of the dying back into the home which works for some but not for others. Hidden within this argument is negation of the impact that space and spatial practices have on both the dying patient and their family whether cared for in the home, hospice or hospital.

The future of palliative architecture

> Palliative care is underdeveloped globally to an extent that it shames us all. Good care at the end of life and a dignified death should be regarded as basic human rights to which everyone has access when the time comes.[8]

In the context of an ageing population that lives longer, receives more medical treatments and dies more slowly, hospice and palliative care buildings have emerged as a new and evolving architectural type. The shift in the hospice movement to privileging hospice home-care is a significant factor in the changing role of the hospice building typology. Many professionals such as palliative and home-care nurses, bereavement counsellors, palliative-care researchers and

educators have emerged and are often accommodated and centralised within new hospice buildings and palliative care units.

Western society's reluctance to think about and deal openly with death has become a world debate. In his 2006 public lecture "End-of-life care around the world: global and local perspectives" David Clark, points out the global need for continued development of hospice services:

> Where the need is the greatest, the fewest hospice and palliative care services exist. There is unrelieved suffering on a mass scale and the efforts of a handful of activists to promote palliative care globally are often ignored and unsupported.[8]

It is likely, as judged from the current media coverage, that future public and government support will be increased along with facilities to accommodate the needs of terminally ill patients and the staff that support them will multiply globally.

However, despite significant research into palliative care from a nursing and psychological standpoint, discussion and research into the architectural and spatial implications of hospice and palliative care has been limited. Recent design guidelines provide a valuable resource to clients and architects designing hospice buildings but leave a gap in the discussion on the idea of hospice space. Verderber and Refuerzo's 2006 book *Innovations in Hospice Architecture*[9] and Ken Worpole's 2009 book *Modern Hospice Design: The Architecture of Palliative Care*[10] are important milestones in the development of the argument for the need to establish, rather than dismiss, the idea of hospice space and its associated spatial practices.

While the "homely" hospice was conceived initially as a reaction to earlier hospitals, contemporary palliative architecture has developed its own unique agenda in response to societal changes to death and dying, a development that represents the coming of age of the hospice as a new architectural type. Not only is the hospice now considered "innovative" architecture within texts such as Verderber and Refuerzo's but also this holistic approach of blending the hospice philosophy and its associated spatial-design issues is set to influence how mainstream hospitals are designed and managed. Initiatives such as the Irish Hospice Foundation's "Hospice Friendly Hospitals Programme" (HFH), launched in 2007, seeks to explore the influence that hospice systems and settings can have in improving the way hospitals deal with death and dying. The HFH theme "Design and Dignity" deals specifically with spatial issues and challenges the way the hospital setting deals with dying. Thus, the hospice, initially conceived in response to failings of the hospital environments, has turned full circle to affect how hospitals are conceived in the future.

Conclusion

Death was rarely mentioned in past hospital architecture texts and, as a result, was largely ignored or hidden in the hospital building. This omission led to questioning of whether or not the hospital was a suitable environment for the dying and led to the development of the hospice. The place of death moved full circle over the last century — from home to hospital, then from hospital to hospice, then from hospice to home; and now it is set to spiral positively in a movement to hospice, home and hospital. From its early beginnings the hospice movement was concerned with providing compassionate care within a "home" for the dying. The contemporary modernisation of the movement has led to the development of competence alongside compassionate care standards within many settings.

With the widespread provision of hospice home-care services, there has been a shift toward providing both in- and out-patient services, supported by continuing education and research programmes related to the care of the dying. In response, the contemporary hospice has become a new type of hybrid building, reaching out *into* the community and housing an extended hospice community that includes patients, families, nursing staff, social workers and visitors and also often includes palliative research, education and bereavement services. Hospice care has moved a long way from providing a "home for the dying" and illustrates society's changing attitudes to death.

The development of the modern hospice philosophy in the 1960s, along with the establishment of hospice home-care services in the 1970s, gave rise to a major shift in thinking, with claims that the hospice is not a building but a philosophy of care. The trend toward hospice care at home has gained popularity and supports this claim; nonetheless, the consequential funding shift has, in some cases, resulted in restricted in-patient hospice beds. Therefore in these hospices admittance to in-patient care is predominantly used for patients either with severe, unmanageable symptoms or those whose family circumstances do not allow home-care. Whist home is generally the preferred place of death, it relies on the traditional model of home, family and community, even as home and family structures have changed considerable in modern society. Homes no longer accommodate extended or multigenerational families and death is not envisioned in the design of home.

Families have also changed with increased geographic mobility, higher divorce rates and greater economic demands placed on women to return to work. All these factors adversely affect the suitability of home as a suitable place for dying and family as a suitable carer.

The suggestion that "architecture is mute" if it is in a collision with medicine,[11] is put to the test by the potential collision between palliative medicine and palliative "space," often resulting in the space being considered silent. What is required is further investigation into the conceptual, architectural and spatial practices that underpin hospice and palliative care, especially in the design of the home, so that the notion of space, rather than building, can make a meaningful contribution to the holistic philosophy.

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CONFLICTS OF INTEREST

The author declares that she has no competing interests