

## CREATING SACRED SPACE FOR HOSPICE PATIENTS IN NURSING HOMES

Creating Sacred Space:  
How Hospice Improves Quality of Death  
In Nursing Homes

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*Abstract*

The nursing home is increasingly the site of death for elderly Americans. Reported experiences at end of life acknowledge the components of a good death, which are consistent with the hospice philosophy of palliative care in a supportive and comfortable environment. Despite this, few nursing home residents die in the care of hospice.

Nursing home residents usually live with roommates. Cohousing inhibits the ability of loved ones to be there, be in comfort and at ease, while it forces roommates to participate in the dying process involuntarily. This process of transformation at end of life is best facilitated in private space where loved ones, staff and other residents can experience the supported death that is marked by dignity and peace.

*Introduction*

To provide a high quality of life for those frail elderly and chronically sick individuals who live in long-term care, we must consider providing them with a high quality of death as a means to ensure their autonomy, personhood, dignity, and a peaceful transition. Nearly 25% of older adults die in long-term care (Munn et al, 2008) and that

number is expected to rise to 40% by 2020 with the swell of the baby boom (Forbes-Thompson & Gessert, 2005). Nursing homes are focused on rehabilitation and restoration, which often results in death-denying behavior and motivates the transfer of dying residents to hospitals for treatment. Thus, as many as 30% of hospital deaths involve persons transferred from long-term care facilities who die within three days of hospital admission (Sloane et al, 2003). Medicare expenditures on acute care hospitalizations for beneficiaries who die reach 30% of the total annual budget. Because the preferential care of hospice is holistic comfort care, providers address physical comfort of the patient and the emotional needs of the caregivers so hospitalizations at end of life are avoided and expenditures significantly reduced (Miller, et al. 2004).

Studies of quality of death have illuminated significant themes and practices that improve the end-of-life experience. The most frequently cited are advance care planning, communication across the care continuum, pain management, dignity, the role of the family, and being there, (Munn & Zimmerman, 2006). While the number of nursing home residents receiving hospice care is growing, their length of stay is shrinking, which indicates inadequate palliative care, postponed end-of-life diagnoses (Bercovitz et al, 2004) and reduced quality of death.

Finally, the work of dying is intimate and spiritual as well as medical, making returning the sacred to the act of dying (Anderson, 2001) a reminder of the philosophy on which hospice was founded. Along with the deeply personal work of transitioning out of the body, the loved ones who support the dying person are coping with their own tasks of letting go, healing, reconciliation, grief and loss. These powerful processes occur more easily and deeply in a private space.

### *Components of a High Quality Death*

In order to provide residents with a good death, we must understand the components that facilitate it. Commonly sited components of a good death are the following: family support, (Munn et al, 2008), outcomes that are consistent with desires (Reynolds et al, 2002) as chosen in documented advance care plans (Teno et al, 2007), with a named decision-maker (Munn et al, 2007), emotional as well as physical support

and comfort is provided (Teno et al, 2004), psycho-social and spiritual needs are addressed (Ersek, 2003), personal hygiene is addressed, physician acceptance of death (Keay et al, 2003), and knowledge of the person (Munn et al, 2007), implementation of palliative care and hospice (Welch et al, 2008), being cared for by compassionate caregivers (Munn et al, 2007) who respect the dignity of the person (Munn et al, 2007) and who receive ongoing training in end-of-life care (Rice et al, 2004), an indication of preparedness to die and the appearance of peacefulness (Munn et al, 2007).

Every person should have access to what he and she defines is a *good death*, though that may be “one of ten thousand doors for men to take their exits” (Nuland, 1993, p.xvii). McCullough says it is “an expected, supported, well-attended death in a location of choice” (2008, p. 196).

For Webb,

“Those deaths that seem good often have these things in common: excessive treatment—treatment that extends the process of dying longer than a patient wants it extended—is not given; pain and other disquieting or humiliating symptoms are managed aggressively and well; the dying person is granted as much decision-making power as he or she wants; emotional issues are addressed; and the patient, his family, and his friends get all the psychological, spiritual, and physical help they need.” (Webb, 1997, p. 28-9).

The following conceptual model was developed from research for an extensive survey of family members’ experience with dying comparing quality of death in the last place of care:

“High-quality end-of-life care results when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings” (Teno et al, 2004).

Munn et al (2008) identified five themes in the end-of-life experience in long-term care. Their first theme described the components of a good death in long-term care as:

“one of comfort, dignity, and closure. Within this theme there were sub-themes of physical symptom management (e.g., ‘being kept comfortable’), circumstances of death (e.g., ‘short in duration, not hanging on,’ ‘not hooked up to machines,’ acceptance of death and giving permission to die), spirituality (‘God here I am. Go ahead and do what you need to do.’), dignity (attentiveness to issues of incontinence), and lack of family burden (e.g., relieving family burden was a motivation for initially moving into long-term care).”

Within these descriptions are clearly identifiable components that collectively result in an image of the elements of a high quality of death to which nursing homes, as a primary location of death, must aspire to for their residents. The provision of these elements is secured by integrating palliative care and hospice care into the resident’s plan of care early enough to benefit the care recipient and the care givers.

#### *Preparation*

Although advance care planning is frequently cited as contributing to high quality of death (Lopez 2007), nursing home staff is not adequately trained in advance care planning (Hanson 2002), families are unaware of the need for planning, residents are not given the time to learn about the value of advance directives, many residents have dementia and cannot complete advance directives, and in some cases advance directives are not honored (Munn et al, 2007).

#### *Palliative Care*

Hospice does a better job of providing pain control than does the nursing home (Trotta 2007), but the nursing home staff must collaborate and facilitate medication protocol. Untreated chronic pain is present in 45 to 83% of nursing home residents (Erseck 2003) yet palliative care and hospice is not prescribed adequately or in a timely manner. Even when offered, nursing home staff often manages palliation poorly. (Erseck 2003) (Lopez 2007) (Munn & Zimmerman 2006) (Munn et al 2007) (Reynolds 2007) (Trotta 2007). Alleviation of residents’ pain is confounded by high rates of dementia in nursing home residents who are unable to make accurate reports of pain and

staff issues such as inadequate skills, poor training and high turnover (Erseck 2003) contribute to insufficient pain assessment. Persons in institutional residential communities and assisted living facilities were more likely to be able to speak and write during the last month of life than nursing home residents (Sloane et al, 2003). Thus, resident experience of untreated chronic pain in the last three months of life may be as high as 86% (Lopez 2007).

### *Hospice Improves Quality of Death*

Although hospice service use in nursing homes has increased nine fold between 1991-1992 and 1999-2000, the 2004 National Nursing Home Survey (Bercovitz et al, 2004) found only 2.4% of current residents receiving hospice care. The objectives of hospice care seek to identify and document goals of care, manage symptoms and pain, attend to psycho-spiritual needs, prevent suffering, and address issues of grief and bereavement for both the patient and the caregivers (Ersek and Wilson, 2003).

While loved ones often fear or deny the death of the person for whom they care, they do know that death will arrive eventually. Yet one of the most secure obstacles to admission to hospice care is the denial of death by caregivers, which underlies the reluctance to identify individuals as dying (Parker-Olive, 2002). This denial prevents the necessary preparation that facilitates high quality of death and often results in suffering and sudden, unexpected death (Miller et al, 2004). Another imbedded obstacle is the unwillingness of physicians to identifying the resident as dying (Rice et al, 2004) thus preventing admission to hospice and the consequent change in plan of care from aggressive treatment to palliative care and hospice.

The holistic approach of hospice care provides a dimension of care that is essential to high quality of death (Trotta 2007). By inviting the services of hospice, everyone involved is made aware of the value of limited time and the need to prepare for death. By accepting hospice care, the person becomes the center of care rather than the disease. Hospice is able to manage symptoms that accompany end of life, such as pain and apnea, more effectively than the nursing home which is subject to regulations and directives that aim to restore and rehabilitate the resident (Forbes-Thompson and Gessert, 2005) and not to support the dying process.

With hospice caring for a resident, the process of anticipatory grief begins and the process of letting go is encouraged by the mere presence of the supportive activities provided by hospice caregivers. The hospice staff is vigilant as death nears, recognizing the signs of imminent death, increasing symptom management and alerting loved ones.

### *Family Support*

One study analyzed family members as an average of 61 years of age; two-thirds were adult children; 19% were other family members such as nieces, nephews and grandchildren; fully 50% worked full-time (Munn et al, 2007) proving that caregiving is a cross-generational experience with widespread implications. Families are the most frequent source of reporting on the death experience of their loved one. It is the family who will carry the experience of their loved one's death through their own life, learning from it.

Many individuals become surrogate responders for loved ones who have lost the capacity to speak for themselves, a role that is often performed with no guidance from the care recipient either directly or by written advance healthcare directives. The inability of residents to communicate their wishes for end-of-life care often results in family conflicts over medical decisions, can exacerbate sibling rivalry and may foster death denial which then manifests in aggressive medical treatment being given to the resident receiving care (Lopez 2007).

### *Staff*

Residents often consider staff to be family, and staff members often consider themselves as family. However, high turnover caused by poor salaries, high stress, low status, paperwork burdens and unresolved grief issues adversely affect quality of life and death for nursing home residents (Ersek 2003). Despite the constant presence of paid caregivers and an increasing presence of hospice personnel in nursing homes, more than half of the dying experience death with no one present (Sloane et al, 2003). The value of being there (Munn and Zimmerman, 2006) for the dying includes staff, who are often unavailable to be present for more time than is allowed to accomplish the required daily tasks of their jobs under the constraints of the facility regulations. Staff become attached

to residents and wish to be there for them through death, which facilitates their grief, which is so often unrecognized.

### *Creating Sacred Space*

Demand for different levels of care in response to the many elderly experiencing the slow declining ability to function fully has given rise to the growth of residential community and assisted living facilities. These are also becoming a location of death where nearly one-third of residents remain until they die (Sloane et al, 2003).

Traditional design in nursing homes requires residents to share a room with at least one other person. As death becomes imminent and loved ones wish to gather, there is a need for privacy, which is difficult to find (Forbes-Thompson 2005). This is the time to gather the supporters and provide private space to facilitate the need of family and staff for “being there” with the person who is dying (Munn and Zimmerman, 2006).

A private room in the dementia unit at The Vermont Veteran’s home has improved quality of death for the residents, families and staff (Simard 2007). By providing privacy and comfort for the person who is dying and for those supporting her or him, we are supporting the transformational process of dying as something personal and valuable. We thus experience the ritual of vigil and create a sacred space for dying.

### *Conclusion*

In the United States, death occurs for most people in hospitals and nursing homes, which are mandated to provide life-saving, death-delaying treatments, resulting in prolonged dying. The consequences of this practice and its denial of dying are that many die alone, in pain and with no control over their end-of-life experience.

For nursing homes, these consequences result in a high incidence of residents who do not receive hospice care although they are eligible for it. Low rates of advance directive completion often complicate identifying those residents at risk for death. High rates of untreated chronic pain have been recognized in nursing home residents at end-of-life. High turnover in staff, low salaries and inadequate training in end-of-life care result in poor care of dying residents. Not only residents, but family members and loved ones are often unprepared for death even when it is expected.

New policies are needed that direct nursing homes to assess end-of-life conditions earlier and provide appropriate palliative care and hospice care for residents. Pain management must become the highest priority. Families need to be made a part of the planning process from resident admission through the dying process. Advance care planning should become an automatic and frequently reviewed experience for nursing home residents and their caregivers. Education about hospice care needs to be available to staff, families and residents on a continuous basis. Increasing salaries, job value, training in end-of-life care skills, and providing bereavement services will improve staff turnover and quality of care for the dying. Changes must be fostered in the culture that move dying out of the realm of medical failure and into its rightful place as a natural, universal experience of transition.

We must recognize the need of loved ones, staff and other residents to be there for the dying. To do this, we need to provide a special place, a sacred space, where loved ones can be present for the dying and the dying can die with dignity and in peace.



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