



Social and organizational practices that influence hospice utilization in nursing homes

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ABSTRACT

Hospice has grown considerably but the likelihood that someone gets hospice depends on social and organizational practices. This article shows how staff beliefs and work routines influenced hospice utilization in two nursing homes. In one, 76% of residents died on hospice and in the other 24% did. Staff identified barriers to hospice including families who saw hospice as giving up and gaps in the reimbursement system. At the high-hospice nursing home, staff said hospice care extended beyond what they provided on their own. At the low-hospice nursing home, an influential group said hospice was essentially the same as their own end-of-life care and therefore needlessly duplicative. Staff at the high-hospice nursing home proactively approached families about hospice, whereas staff at the low-hospice nursing home took a reactive approach, getting hospice when families asked for it. Findings demonstrate how staff beliefs and practices regarding hospice shape end-of-life care in nursing homes.

Introduction

In 2014 the [Institute of Medicine, 2014](#) released *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, a comprehensive report that showed the U. S. health care system often fails to meet the needs and preferences of patients near the end of life. The health care system is designed, the report explained, to extend the lifespan at almost any cost without adequate attention on ensuring that death occurs with as little pain and suffering as possible. In the report, the IOM recommended expanding access to comprehensive palliative care, reducing financial disincentives for hospice enrollment, and developing standards of communication regarding advance care planning ([Unroe, Ersek, & Cagle, 2015](#)). Nursing homes are one of the main clinical settings where these challenges occur. With 1.8 million individuals currently residing in nursing homes, most of whom are there for long-term care, it is important to consider the role of nursing homes in ensuring quality end-of-life care ([Ersek & Carpenter, 2013](#)). In this article, we examine social and organizational practices that encourage and discourage hospice utilization in nursing homes.

Over the last fifteen years, palliative care has been among the fastest growing sectors of the U.S. healthcare system ([Hughes & Smith, 2014](#)). Given that the overall population is getting older and living longer with chronic disease, the need for palliative care is likely to keep growing for the next several decades ([Saracino, Bai, Blatt, Solomon, & McCorkle,](#)

[2017](#)). Palliative care provides comfort to individuals at any stage of a life-limiting or life-threatening illness. It focuses on alleviating the symptoms of illness and the side effects of treatment, as well as providing social, psychological, and emotional support to patients. Palliative care can begin at diagnosis and continue throughout the provision of life-extending treatments.

Hospice is one form of palliation. Hospice provides comfort care for individuals who are likely within six months of death. Hospice is often implemented later in the illness trajectory than palliative care, after all life-extending treatment options have been considered. At that point, the focus turns to pain management and attending to the social, psychological, and emotional needs of patients and their loved ones throughout the dying process and into bereavement. Hospice care, like palliative care, has grown dramatically in the United States. In 2015 approximately 1.6-1.7 million people received hospice care, with about 90% of them accessing it through Medicare ([Medical Payment Advisory Commission, 2016, 2017](#); [National Hospice and Palliative Care Organization, 2016](#)). That same year 41% of all hospice days occurred in a nursing home and 32% of hospice deaths occurred in a nursing home. While hospices historically were primarily inpatient facilities, now over 70% of hospices are freestanding agencies with staff and volunteers who visit patients at their place of residence. Nursing homes have been a part of this trend, as they increasingly enter into contract with local agencies to provide hospice care. In fact, recent data suggests

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that nearly 20% of all hospice patients live in nursing homes. (National Hospice and Palliative Care Organization, 2016).

Even though hospice has continued to grow, utilization is limited by a range of barriers that include inadequate education about hospice benefits, challenges with implementation, and policy disincentives, among other issues (Aldridge et al., 2016; Gillan, van der Riet, & Jeong, 2014; Miller, 2014; Torres, Lindstrom, Hannah, & Webb, 2016). Furthermore, from the perspective of physicians, end-of-life care is often marked by diagnostic uncertainty, which can result in late referrals for hospice or no referral even when clinically appropriate (Christakis, 2001; Kaufman, 2006). A recent study (Spencer, Mrig, Matlock, and Kessler (2017) noted the hospice “underutilization paradox”, in which the widespread preference for hospice among patients and families exists alongside the reality that most deaths occur without hospice in institutional care such as nursing homes. Furthermore, studies have shown significant variation in hospice utilization among nursing homes (Miller, Lima, Gozalo, & Mor, 2010; Zerzan, Stearns, & Hanson, 2000), suggesting that something going on inside nursing homes shapes whether a person will get hospice when clinically appropriate.

Given these trends in end-of-life care, scholars have examined how clinical staff's beliefs about death and dying shape their perceptions of hospice care. Hospice utilization has been shown to reflect nursing homes' staff attitudes towards end-of-life care (Zheng, Mukamel, Caprio, & Temkin-Greener, 2013). A recent survey of nursing home staff, for example, suggested that managers and floor staff held different attitudes towards end-of-life care, and those differences influenced resident care (Leclerc et al., 2014). Another study compared physicians and hospice nurses' attitudes towards hospice, finding that both agreed on the characteristics of a “good death” but that physicians were significantly less likely to express support for patient control over end-of-life care (Bakanic, Singleton, & Dickinson, 2016).

Scholars have found links between care workers' attitudes towards dying and their attitudes towards patient care at the end-of-life. For instance, a recent study showed close associations between care workers' experiences with death in their personal lives and their ability to comfort dying patients (Wessel & Rutledge, 2005). Knowledge about palliative care also plays a role in care workers' attitudes, as higher hospice utilization in nursing homes is associated positively with staff knowledge level about end-of-life care (Unroe, Cagle, Lane, Callahan, & Miller, 2015). The present study builds on the existing scholarship, examining how attitudes towards hospice care shapes policies and practices and may influence if and how hospice is utilized.

As hospice utilization in nursing homes has increased, researchers have also assessed residents' family members' impressions of hospice. Studies show that families believe hospice services in nursing homes improve symptom management, reduce pain and hospitalizations, and provide for overall improved quality of life compared to dying without hospice (Baer & Hanson, 2000), and this belief has been empirically validated (Miller, Gozalo, & Mor, 2001; Miller, Mor, Wu, Gozalo, & Lapane, 2002). Family members of nursing home residents who are on hospice report similar levels of anxiety and depression as family members of community-dwelling hospice patients, but have additional concerns related to the overall quality of nursing home care and the level of coordination between hospice and nursing home staff (Hwang et al., 2014; Oliver et al., 2014). While families like having hospice services available in nursing homes they also desire a clear distribution of responsibilities among involved staff members. Research highlights the need for clear and open communication with residents and family members to minimize role confusion in these settings (Gage et al., 2016).

The literature reviewed above provides the context for the present study, which examined social and organizational practices that shaped hospice utilization in two nursing homes. Both nursing homes were in the same state, part of the same for-profit company, and had the same policies and access to hospice services, yet they varied substantially in their hospice utilization rates. Our analysis centers on differing staff

attitudes towards hospice and organizational practices in initiating hospice between the two facilities. Staff at both nursing homes noted familial and financial barriers to hospice, and explained that in such cases the nursing homes provided their own in-house end-of-life care. While staff at the high hospice nursing home said hospice was an additional benefit that went beyond the nursing home's capabilities, at the low hospice facility, an influential group of staff that included the medical director and director of social services said the nursing home offered end-of-life care that was essentially the same as hospice and therefore needlessly duplicative. In addition, staff at the high hospice facility took a proactive approach towards initiating hospice, raising the issue with residents and families when it was clinically appropriate, while staff at the low hospice facility took a reactive approach, waiting for residents or family members to ask about hospice.

Methods

This study is part of a larger study about end-of-life care decision-making in nursing homes (Boerner, Rodriguez, Quach and Hendricksen, 2018). We conducted interviews with staff in two nursing homes located in Massachusetts and part of the same large, for-profit firm. The nursing homes had the same policies and a stated commitment to compassionate, comprehensive care including hospice services when appropriate and in-house end-of-life care when hospice was not utilized. While the nursing homes were similar in these and other respects, there were also some notable differences that form the basis of our comparative case study. Most importantly for this study, the nursing homes differed in their hospice utilization rate. Based on 2016 data from the nursing homes, at Site 1, 76% of all deaths occurred while residents were on hospice, while at Site 2, 24% of all deaths were on hospice. Hospice utilization was measured as the ratio of the number of deaths on hospice to total deaths. In other words, at Site 1, 76% of people who died were on hospice at the time, while at Site 2 just 24% who died were on hospice.

The nursing homes provided care to somewhat different populations. Site 1 had a higher proportion of long-term care residents, while Site 2 had a higher proportion of post-acute care residents. Long-term care residents typically live in the nursing home until they die, while post-acute residents get rehabilitation and 24-hour skilled nursing care with the goal for the individual to leave the nursing home and go back to their home community. In addition, Medicaid typically pays for long-term care, while Medicare pays for up to 100 days of post-acute care as long as the resident's condition shows improvement. These differences influenced what we observed with respect to hospice care, but they do not account for the difference in hospice utilization. While it is the case that one site had more long-term care and the other more post-acute, those who died were not any less in need of hospice. Taken together, these dimensions of variation create meaningful comparisons that shed new light on the role of social and organizational processes in hospice utilization.

Between January and May 2017, we interviewed staff members at both nursing homes who had a role in hospice utilization. Our sample included 21 staff members, 10 at Site 1 and 11 at Site 2. We interviewed staff in a wide variety of positions, including Director of Nursing (2), Unit Manager (4), Floor Nurse (2), Reimbursement Coordinator (2), Director of Social Services (2), Social Worker (2), Medical Director (2), Administrator (1), Assistant Administrator (1), Nurse Educator (1), Manager of Clinical Operations (1), and CNA (1). Accessing this range of vantage points provided a holistic picture of factors that shape hospice utilization.

The qualitative, in-person interviews generally took between 30-60 minutes. We practiced responsive interviewing, meaning that interviews were like extended conversations, and the questions and specific issues discussed varied depending on who was being interviewed and their position in the nursing home (Holstein & Gubrium, 1995). A strength of this approach is that the researchers approach the interview

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