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"This is our last stop": Negotiating end-of-life transitions in assisted living

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ABSTRACT

Where people die has important implications for end-of-life (EOL) care. Assisted living (AL) increasingly is becoming a site of EOL care and a place where people die. AL residents are moving in older and sicker and with more complex care needs, yet AL remains largely a non-medical care setting that subscribes to a social rather than medical model of care. The aims of this paper are to add to the limited knowledge of how EOL is perceived, experienced, and managed in AL and to learn how individual, facility, and community factors influence these perceptions and experiences. Using qualitative methods and a grounded theory approach to study eight diverse AL settings, we present a preliminary model for how EOL care transitions are negotiated in AL that depicts the range of multilevel intersecting factors that shape EOL processes and events in AL. Facilities developed what we refer to as an *EOL presence*, which varied across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EOL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EOL processes and events, including how deaths were communicated and formally acknowledged and the impact of death and dying on the residents and staff. Our findings indicate that in the majority of cases, EOL care must be supported by collaborative arrangements of care partners and that hospice care is a critical component.

Introduction

Where people die has important implications for end-of-life (EOL) care and experiences (Ball et al., 2004; Lynn, 2002). Assisted living (AL), the fastest growing long-term care option in the U.S. and home to more than one million U.S. older adults (Metlife Mature Market Institute, 2011; Mollica, Houser, & Ujvari, 2010), increasingly is becoming a site of EOL care and a place where people die (Golant, 2004; Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006). From 14 to 33% of residents die in AL each year (Golant, 2004; Munn et al., 2006; Zimmerman et al., 2005); nearly half of those in dementia care units (DCUs) remain until death (Hyde, Perez, & Reed, 2008). Additionally, aging (i.e., dying) in

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place is a main tenet of AL philosophy (Hyde et al., 2008), and most residents consider AL their final home (Ball et al., 2004). National data over recent decades indicate an increase in resident length of stay. Data from 1995 report an average tenure of AL residents of 18 months (Hawes, Rose, & Phillips, 1999), whereas 2010 data report a median tenure of 22 months (Caffrey et al., 2012).

Accompanying the growing prevalence of death is the increased frailty of AL residents. Data from a 2010 national survey of AL facilities with four or more beds show that AL residents are entering older and sicker and with greater care needs (Caffrey et al., 2012). The average age at AL admission is 85, and 54% of residents are 85 and older. The typical resident requires assistance with more than one activity of daily living (ADL); more than a third need help with at least three. These data also show the growing presence of comorbidity. Half of residents have from two to three chronic conditions; 26% have from four to ten. Although this survey found that 42% of residents had Alzheimer's disease and other dementias, earlier estimates indicate a prevalence of dementia ranging from nearly half (Ball, Perkins, Hollingworth, & Kemp, 2010) to 67.7% (Leroi et al., 2006).

Despite evidence of increasing resident impairment and death, AL remains largely a non-medical care setting that ideally subscribes to a social rather than medical model of care (Golant, 2008), although little data exist as to how many facilities practice this model. The bulk of care is provided by low-wage unlicensed workers with little, if any, training in EOL care (Ball et al., 2010; Stone, 2010). In most states, AL staff are not permitted to provide skilled health care, although more and more AL facilities have licensed nurses on staff. Increasingly, however, states, including Georgia (the site of this study), are making statutory, regulatory, and policy changes that expand levels of AL care (Mollica et al., 2010), thus enhancing AL's ability to accommodate increasing resident frailty and EOL care.

Also relevant to EOL is the expansion of hospice use in AL, principally owing to Medicare and Medicaid benefits but also due to regional market forces and state policies (Mollica et al., 2010). Facility and individual factors that influence hospice use in AL include staff knowledge and attitudes (Cartwright & Kayser-Jones, 2003; Cartwright, Miller, & Volpin, 2009; Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006), point of physician referral (Smith, Seplaki, Biagtan, DuPreez, & Cleary, 2008), and residents' clinical conditions and AL tenure (Dobbs et al., 2006). Evidence exists that hospice services positively affect EOL in AL through improved pain control and higher levels of ADL care (Munn et al., 2006) and greater family satisfaction (Cartwright et al., 2009). Other research found that AL staff view hospice as an important source of training and bereavement services, whereas residents indicated that hospice increases their understanding of death and families value hospice's monitoring role (Munn et al., 2008). Another study found that administrator support for dying in place with hospice, integration of hospice services into facility care practices, and resident–staff relationships were key factors affecting hospice outcomes (Cartwright et al., 2009).

Informal care from families and friends contributes a significant care component in AL (Ball et al., 2004; Ball et al., 2005; Kemp, Ball, & Perkins, 2013; Perkins, Ball, Kemp, & Hollingsworth, 2013; Williams, Zimmerman, & Williams, 2012). Informal caregivers typically provide socio-emotional support and help with various instrumental activities of daily living (IADLs), such as money management, shopping, and transportation to medical appointments, more so than help with ADLs (Ball et al., 2005; Perkins et al., 2013), although spouses living together in AL also provide ADL support (Kemp, 2008, 2012). Our recent research suggests that most AL residents have *care convoys* that include family and friends in addition to formal caregivers and that adapt to changes in residents' care needs and transitions in informal and formal care networks (Kemp et al., 2013).

EOL as a social process

Early ethnographic studies on EOL in nursing homes (Gubrium, 1975; Marshall, 1975a, 1975b; Savishinsky, 1991) and hospitals (Glaser & Strauss, 1965, 1968) point to the usefulness of an interpretive lens when examining EOL. As Marshall (1975a: 355) notes, dying is a "social event" that takes place in a social context. Individuals' experiences while dying, thus, are differently shaped by the nature of their illness and others' reactions to it, by the care provided for their physical, emotional, social, psychological, and spiritual needs, and by the social and physical environments in which they receive care. Likewise, in AL death and dying influence the surrounding social and physical environments and affect others in the setting, whether approaching death or not.

Glaser and Strauss (1968) in their classic treatise on death and dying in hospitals (1968: 6) refer to the socially defined course of dying as a *dying trajectory*. Dying trajectories have both duration (the length of the dying course) and shape (the slope of individuals' decline as they approach death). Dying can be sudden or span days, months, or years. Dying statuses and trajectories are not purely objective, but also perceived (Bern-Klug, 2009; Glaser & Strauss, 1968; Marshall, 1975a). Consequently, stakeholders (i.e., residents, families, friends, AL administrators and workers) may not share perceptions of an individual's dying status or trajectory, or how best to manage EOL care. Bern-Klug (2009), in considering social interactions at EOL, points out the ongoing challenge of determining when an individual is in fact at EOL. Consistent with the Institute of Medicine (2003), we define EOL broadly to include periods of decline associated with advanced age or chronic illness where the timing of death is uncertain.

Notwithstanding AL's changing care landscape, AL largely has been overlooked by researchers studying EOL (Gruneir et al., 2007). Existing research consists primarily of comparisons to nursing home care (Sloane et al., 2003), small qualitative case studies (Rubenstein, 2001; Sanders & Anewalt, 2010), administrator attitudes toward hospice (Cartwright & Kayser-Jones, 2003), and outcomes of hospice use (Munn et al., 2006, 2008). Little is known about the experiences of those dying, how EOL affects a home's social environment, or the way EOL is managed and negotiated among key stakeholders in AL. This article addresses these knowledge gaps. Our specific aims are to: 1) increase understanding of how EOL is perceived, experienced, and managed in AL; and 2) learn how individual, facility, and community factors influence these perceptions, experiences, and processes.