What Impact Do Setting and Transitions Have on the Quality of Life at the End of Life and the Quality of the Dying Process?

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Purpose: The aim of this article was to identify major research needs related to quality of life at the end of life and quality of the dying process for vulnerable older people at home, in assisted living facilities, in skilled nursing facilities, and in prisons. Design and Methods: Review and analysis of the literature was used. Results: The science is generally weak in relationship to what is known about quality of life at the end of life and quality of dying for vulnerable older adults in different settings. Few studies address actively dying patients and the reasons for transfers between home and other settings. Existing studies are primarily anecdotal, descriptive, have small samples, and involve a single setting. Participant decisional capacity is a barrier to conducting research in these settings. Implications: Research recommendations for each setting and across settings are provided. The National Institutes of Health should clarify criteria for enrollment of persons with diminished, fluctuating, and absent decisional capacity in research.

Key Words: End of life, Quality of death, Home care, Assisted living, Skilled nursing facilities, Prisons

Older adults in the United States die in a variety of settings. Although many (43%) indicate that they would prefer to die at home, only 19% of older adults actually do so (Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999). Most older adults die in hospitals. The remainder die in the community and in residential facilities [assisted living facilities (ALFs) and skilled nursing facilities (SNFs)] and, for a small but growing number, in prisons. A small number of older adults receive hospice care at the end of life, the sole health service devoted exclusively to end-of-life care.

Setting has a palpable, direct, and immediate impact on the quality of life that an older adult experiences at the end of life. Where older people die is influenced by demographic factors, diagnosis, and health resources (Fried, Pollack, Drickamer, & Tinetti, 1999; Gallo, Baker, & Bradley, 2001). In turn, setting at time of death exerts an influence on the quality of death. Setting affects the philosophy of care, the types and intensity of services that can be delivered, who controls these services, the relationships of the persons delivering care to the dying older adult, caregiver expectations, skill and availability, and the financing to sustain such care.

In this article, we make the assumption, as have others (Levine & Zuckerman, 2000), that there is a medical responsibility and an ethical obligation to older adults to deliver competent, compassionate care at the end of life—irrespective of setting or disease process. On the other hand, we recognize that the paradigms of care in settings such as home, residential facilities, and prison are not easily reconciled with a standardized vision of comfort and quality care at the end of life. Philosophy, goals of care, and expectations of the patient, family, provider and care setting, the training and availability of providers, and regulatory and financing structures are often at odds with and disruptive to good end-of-life planning in these settings. Thus, we recognize the need to balance what is medically and ethically preferable with what is fiscally feasible and propose that not all services must be available in each setting and that some services are best delivered in a setting such as the hospital.

Transitions also have a profound impact on the quality of dying for older adults. A small number (7% of older people who die) transition to hospice care in their place of residence, the hospital, or an inpatient hospice. Encompassing a philosophy that meets the comfort and spiritual needs of the dying person and their family, the concept of hospice—that is meeting
the special needs of the dying person—is the “gold standard” of quality end-of-life care. But even the transition of dying older adults to hospice differs across settings and diagnoses. Decisions to transfer to hospice are often fraught with conflicts and constraints about appropriateness and timeliness of services. Moreover, Medicare hospice regulations do not permit hospices to adequately address the needs of many older adults at the end of life (Meier & Morrison, 1999).

Most transitions of a dying older adult from home, ALFs, SNFs, and prisons are to the hospital, where 49% of deaths occur. Because substantial data (Covinsky et al., 1994; Meier & Morrison, 1999; Riedinger & Robbins, 1998) document the threats to quality of care for dying older adults in hospitals, this article does not address the hospital setting. Our assumption is that transfers of older people to the hospital at the end of life are not necessarily inappropriate. We recognize that the notion of benefit is value-laden. Where prognosis is uncertain and the benefits of transfer unclear—for example, for those older people with a trajectory of dying related to organ failure (Lunney, Lynn, & Hogan, 2002)—transfer to the hospital is often inevitable and also potentially appropriate. Frail older adults who require both active treatment of an underlying disease and intensive palliation, characterized as “blended care” (Travis, Loving, McLarenahan, & Bernard, 2001) or a “mixed management model of care” (Meier & Morrison, 1999), may also appropriately be transferred to a hospital. On the other hand, many dying older adults who fall into the frail category (Lunney et al., 2002) are inappropriately transferred to the hospital at the “brush of death” (Engle, 1998), where they live out their last moments (Tolle, Rosenfeld, Tilden, & Park, 1999). It is our belief that transitions should be dictated by the needs and desires of patients, not by the resources of the setting. We envision a hierarchy of acceptable reasons for transfer, with patient preference being the most justifiable, but including accommodation to families unable to manage care at home (Arras & Dubler, 1994) and facility characteristics (i.e., staff ability and availability) the least justifiable.

A thumbnail portrait of care at home and in ALFs, SNFs, and prisons brings into bright relief the influence of setting on quality of life and the quality of the dying process and transitions at the end of life.

For an older person at the end of life, home represents continuity, familiarity, and the ability to maintain preferred daily routines and control the conditions for interactions with family and friends and for service delivery. Family members are often present to provide comfort, sustenance, and oversight but rarely feel confident delivering skilled care or managing complicated technologies (Arras & Dubler, 1994; Levine, 2000). Although the need to negotiate for paid caregivers can be cumbersome and time-consuming, these caregivers enter the home as “guests,” where the pace and frequency of services are dictated by the preferences of the older person and family. On the other hand, patients and family face substantial difficulties in finding and sustaining appropriate services and in converting their home into a “hospital” type of environment (Arras & Dubler, 1994). For the most part, decisions as to intensity of services (hospice, transfer to the hospital) are driven by the personal preferences of the older adult and/or their family and by their ability to finance services.

ALFs serve older people too frail to live independently. ALF is a housing or residential option that provides varying levels of personal, supportive, and health care services. The goals of care in ALFs are to maintain and foster independence. Death is the stated reason for discharge for 28% of the estimated 800,000 residents currently in ALFs. In some instances, care at the end of life for a resident in an ALF is characterized by continuity of place of residence. Decisions as to pace and frequency of paid caregiver services in ALFs are shared by the resident, the family, and occasionally, by the facility. Although a few services in ALF are available 24 hr a day, 7 days a week, resident and family preferences as to intensity of services (hospice, transfer to the hospital) are tempered by the ability to pay, facility policies, regulatory statutes, and reimbursement, including Medicaid payment for ALF services.

The stated goal of care in the nation’s 15,600 SNFs is to maximize independence and functionality for a resident who is an average of 83 years of age and physically and cognitively frail (Omnibus Budget Reconciliation Act, 1987). The focus of care in SNFs is on routines of daily care and routines of daily life. Whereas many SNFs do provide hospice care, comfort care, and/or palliative care programs, such care is not their core mission, and generally, SNFs are not organized, funded, or staffed to do so. Twenty percent of all deaths among older adults occur in SNFs (Fried, Pollack, et al., 1999). Care at the end of life for an older SNF resident is delivered by staff caregivers on a schedule and in a manner determined and controlled by the facility. Although 24-hr personal and nursing care services are always available, and personal and family preferences are elicited, the intensity of services (hospice, transfer to the hospital) is primarily governed by facility policies, staff availability and workload, regulatory statutes, and reimbursement.

Prisons are punitive institutions in which the goal of care is confinement and punishment. The care provided is not patient-centered, but prison administration-centered, and thus the patient’s wishes and best interests are not always taken into account. Currently, 1.2% of the nation’s federal and state prison population is 66 years of age and older, and an additional 4.3% are 56–65 years of age. Data on deaths in prisons are not age-specific, and thus we cannot determine the exact percentage of older adults who die in the system (U.S. Department of Justice, 2001). In general, very few studies focus on health care in prison facilities, and those that do tend to focus on HIV/AIDS (Freudenberg, 2001).

The science is generally weak in relationship to what is known about quality of life at the end of life and the quality of the dying process for older people in different settings. This is especially true for the oldest
old (Meier & Morrison, 1999) and across cultural and ethnic backgrounds (Engle, Fox-Hill, & Graney, 1998). Few studies examine actively dying patients or address a specific point on the dying trajectory. The reasons for transfers are complex and not well understood. For the most part, existing studies are anecdotal or descriptive, have a small sample size, involve a single setting or state, use a correlational design, and have insufficient power to detect meaningful clinical differences (Morrison, Siu, Leipzig, Cassel, & Meier, 2000). In prisons, the few studies on quality of life and the end-of-life process are generally narrow and, because of the vast differences between facilities, cannot be applied to prisons as a whole.

In this article, we focus on quality of life at the end of life and the quality of the dying process for vulnerable older people at home, in ALFs, in SNFs, and in prisons. (We have chosen to focus on SNFs, ALFs, and prisons because these are settings in which there is a body of literature, albeit small, on quality of care at the end of life and the quality of the dying process for vulnerable older people. Regarding Native Americans, Dr. Judith Kitzes is currently conducting research on place of death, hospice use, and hospitalization at the end of life. Regarding residents in chronic disease hospitals, we found no data on end-of-life care in these facilities.) For each setting, we begin with an overview of end-of-life care. We next examine the state of the science related to end-of-life care, referencing quality indicators potentially amenable to intervention (Morrison, Siu, et al., 2000), including physical symptoms, advance directives, hospice services, transitions to acute care hospitals, and staffing. We also address macroissues (regulations, financing, and hospital occupancy) known to exert an impact on setting and transitions for older adults at the end of life. Finally, across all settings and for each setting, we identify major research needs to address the most critical issues for end-of-life care for these vulnerable older adults.

Care at Home

Overview

Included in the vast literature analyzing patterns of caregiving in home care, but beyond the scope of this article, is recognition of the lack of support for unpaid family caregivers (Ferrell, 2001; Levine & Zuckerman, 2000; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Despite older people’s expressed preference to die at home, only 19% of older people die in their homes. The number of these deaths that are planned as home deaths is unknown. Older people who die at home are more likely to have certain demographic characteristics, diagnoses, and access to health resources. Older women who are married, have a higher socioeconomic status, are more impaired, and have a longer period of illness are more likely to die at home (Fried, Pollack, et al., 1999; Gallo et al., 2001), as are older patients with a diagnosis of cancer. Gallo and colleagues (2001) found that 29% of older patients in Connecticut with a diagnosis of cancer died at home. Moreover, home deaths are more common in locations in which hospice services are more available and in which hospital occupancy rates are high (Gallo et al., 2001; Pritchard et al., 1998).

In 1996, approximately 2.5 million adults received services daily from 13,500 Medicare and Medicaid certified home health agencies and hospices. On average, 72% of all home health patients are 65 years of age and older, and 30% of all patients are 85 years of age and older (Haupt, 1998b). In home care, 4% of patients are listed as having died as the reason for discharge (Haupt, 1998a).

State of Science

Pain and Symptom Management.—The pain literature clearly supports that pain is subjective and that all patients deserve to be assessed for pain and to have their pain adequately treated (Joint Commission on Accreditation of Healthcare Organizations, 1999). Nevertheless, irrespective of setting (home, ALFs, SNFs, and prisons), there is evidence that older people themselves, family members, and paid staff members are conflicted about how to achieve adequate pain management at the end of life (Agency for Health Care Policy and Research, 1992; Ferrero, 1999) and are concerned about the adequacy of pain management, risk of addiction, and fear of hastening death. Family members and paid caregivers have been known to undermedicate and/or to refuse to administer opioids for fear of addiction (Agency for Health Care Policy and Research, 1992; Ferrero, 1999). Physicians are reluctant to order sufficiently large doses or standing orders for opioid medications for fear of regulatory oversight and threats to their medical licenses (Mezey, Miller, & Linton-Nelson, 1999; Shapiro, 1994a, 1994b; Von Roenn, Cleeland, Gonin, Hatfield, & Pandya, 1993).

Several studies question pharmacists’ knowledge in dispensing controlled substances (Joranson & Gilson, 2001) and the availability of pharmacy services. Older people living in high-risk neighborhoods in one city were unable to procure necessary pain medication because the pharmacies did not stock opioid narcotics (Morrison, Wallenstein, Natale, Senzel, & Huang, 2000). Staff members, and possibly families, fail to request and provide analgesia to older people with dementia under the assumption that these people do not experience pain (Ferrell, Cohen, Rhiner, & Rozek, 1991). Home care and facility staff members are unfamiliar and/or uncomfortable with the concept of “double effect” when administering opioid analgesics (Zenz, 1991).

Nutrition continues to be one of the most morally and clinically complex and troubling areas in the care of dying older people (Burger, Kayser-Jones, & Bell, 2001). Data on nutrition and hydration for dying older people at home are extremely limited. Mezey and colleagues (1999) found that whereas many spouses of older people with dementia cared for at home were willing to forgo cardiopulmonary resuscitation (CPR)
and ventilators, far fewer were willing to forgo tube feedings. We know little about the use of total parenteral nutrition or enteral feedings for older adults cared for at home at the end of life.

Dyspnea is a well-known symptom of at the end of life, occurring in 50% of persons (Morrison, Siu, et al., 2000). We found no study that specifically examined the management of dyspnea in older people dying at home.

**Advance Directives.**—Studies of the effectiveness of the use of advance directives [e.g., living wills, durable power of attorney for health care (health care proxies), do not resuscitate (DNR) orders] have yielded inconsistent data as to the usefulness of these documents for older people dying at home. DNR orders have their maximum impact where states have established procedures for emergency personnel to accept these orders (Sabatino, 1999). Many authors (e.g., Emanuel & Emanuel, 1998; Teno, 1998) emphasize that advance directives are most effective when used to promote patient-provider communication.

**Hospice.**—Eleven percent of older people who die at home are receiving Medicare home hospice services (Meier & Morrison, 1999). In 1996, nationally, 78% of all of the 60,000 receiving hospice services were 65 years of age or older and 21% of all of the 60,000 (Meier & Morrison, 1999). In 1996, nationally, 78% of all of the 60,000 receiving hospice services were 65 years of age or older and 21% of all patients were 85 years of age or older (Haupt, 1998b). Women who live with a family member are more likely to receive home hospice than other older patients with a comparable diagnosis. Almost 50% of all older people with cancer receive hospice services prior to their deaths (Lunney et al., 2002). Patients receive an average of 48 days and a median of 29 days of hospice care [not specific to home hospice or older adults; National Hospice and Palliative Care Organization (NHPCO), 2001].

Receiving hospice care substantially increases the chance of dying at home for people of all ages, including older people. Of all home hospice patients, 77% of “discharges” die at home (NHPCO, 2001). Other home hospice recipients are transferred to the hospital or to an SNF.

Use of hospice by community-residing older adults is influenced by the same factors that generally influence hospice use: lack of familiarity with the hospice benefit, failure of providers to make a hospice referral, unwillingness of the patient to agree to the clinical requirements for accessing hospice benefits, and lack of availability of services (Fried, Pollack et al., 1999; Pritchard et al., 1998; Sims, Radford, Doran, & Page, 1997). There is some evidence that professional nurses working in home care delay transferring their older patients to hospice because of the desire to maintain continuity of services and because they feel that they can provide services comparable with hospice (Schim, Jackson, Seely, Grunow, & Baker, 2000).

**Hospital Transfer.**—For older adults dying at home who are not receiving hospice, we know little about transfers to hospital. In one study, older people were more likely to die at home when they were in a physician house call program (Fried, Pollack et al., 1999).

**Assisted Living Facilities**

**Overview**

At present, there are slightly more than 30,000 ALFs with slightly less than 800,000 residents in the United States. The mortality rate in ALFs is estimated to be approximately 28% annually [National Center for Assisted Living (NCAL), 2001]. The most common discharge destination from an ALF is to an SNF (20–43%; Phillips, Hawes, Spry, & Rose, 2000). The NCAL study (2001), reported that 12% of ALF residents returned home, 14% moved to another ALF, 11% were hospitalized, and 28% were deceased. Of ALF residents reported as having died, the data are unclear as to whether the resident died in the facility or was transferred to an SNF or hospital before death. ALFs are the fastest growing housing sector for frail older adults, and as such there is growing concern about the quality of life at the end of life and the quality of dying for ALF residents. Known by as many as 10 different licensure names, most commonly “board and care,” an ALF is a housing or residential option with personal, supportive, and health care services for older adults too frail to live independently yet not requiring skilled nursing services 24 hours a day. Slightly less than 50% of residents move to an ALF from home, 16% from another ALF, 16% from a hospital, and 10% from an SNF or independent living facility.

Most ALFs are for profit; many are chain owned. Most residents are private pay with the average monthly room, board, and services fee ranging from $1,500 to $2,500/month. Thirty-eight states provide Medicaid reimbursement via a home and community-based services waiver or the state Medicaid plan, but only for the personal and nursing or health care portion of the services. Approximately two thirds of ALFs are free standing, 30% share a campus with an SNF, and the remainder are on a campus with independent living, congregate apartments, or a continuing care retirement community (CCRC). Thirty-seven percent of ALFs have special care units for residents with dementia and/or Alzheimer’s disease (Hawes, Rose, & Phillips, 1999).

The average ALF resident is 80 years old, female, White, widowed, independently ambulating but requiring assistance with two activities of daily living (ADL), and most commonly self-bathing and self-dressing; slightly less than 20% of residents need assistance with three or more ADLs. The range of residents with moderate-to-severe cognitive impairment is reported to be between 25% and 33% (Hawes et al., 1999; NCAL, 2001). Of facilities responding to a 2000 NCAL survey, approximately 12% of residents have early-stage Alzheimer’s disease, 12% have late-stage Alzheimer’s disease, 25% are mildly affected by other dementia, 4% are severely affected by other dementia, 10% have mental retardation or another
developmental disability, and 24% have signs of or are being treated for depression. Among the medical conditions characteristic of the ALF population, 28% have heart disease; 16% osteoporosis; 13% diabetes; 11% are poststroke; and 5% have Parkinson’s disease, cancer, or multiple sclerosis. One third of residents are incontinent of urine and 18% of bowel.

Compared with SNFs, which are regulated and monitored by federal and state agencies, ALFs are under the purview of state housing regulations, licensing, or certification. Survey and monitoring vary among states. Many states stipulate the conditions under which residents are admitted and discharged, and have special requirements for residents with dementia or special units. ALFs are not required to admit residents even when they meet state regulations for admission (e.g., New Jersey) and, conversely in some states, ALFs can choose to retain residents whose care needs exceed the ALF’s license or certified level of care (e.g., Michigan).

The goal of the ALF is to encourage and promote independence, autonomy, dignity, and choice with a degree of shared risk and responsibility for personal care negotiated between the provider and the resident (tenant). ALFs generally endorse a concept of “aging in place,” whereby a resident can receive additional services as needed in the facility. Many states have revised their regulations to facilitate and pay for aging-in-place services through Medicaid and other programs. The concept of aging in place is now in contention, with some ALFs questioning whether aging, and hence dying, in place, are operationally as well as financially viable (Hawes et al., 1999). On average, length of stay in an ALF is slightly less than 3 years. This may be misleading, however, because most ALFs have been in operation for less than 10 years.

State of Science

We know virtually nothing about the quality of end-of-life care and the quality of dying for ALF residents. One study (Mitchell & Kemp, 2000) found that, as the number of chronic illnesses increased, the quality of life for ALF residents decreased, but this study did not address quality of life for ALF residents who were dying. A new, National Institutes of Health-funded study (Zimmerman et al., 2001) is comparing the structure and process of end-of-life care in ALFs and SNFs.

ALFs have the capacity to assist residents with ADLs and instrumental ADLs, medication administration, perform health assessments, and conduct health monitoring; but whether this applies to residents at the end of life is unclear. Nursing services are provided or arranged by as many as 90% of facilities, but this varies from basic nursing tasks to those requiring registered nurse (RN) supervision and delegation, not uncommonly by licensed or certified home health agencies. Many states permit residents who require skilled nursing to remain in the facility for limited conditions and for short periods of time. In some states, there are associated additional fees (or Medicaid rates) with the provision of skilled nursing provided by the facility staff or, more usually, by contract professional staff members. In general, physician attendance and oversight are resident-specific; some ALFs on campuses with a nursing home or part of a CCRC obtain physician coverage through those avenues.

Pain and Symptom Management.—Of all ALFs, nationally, 78% allow residents to remain in the facility if they need oxygen, 63% of facilities allow residents with urinary catheters, and 21% allow residents with tube feedings. These services are either paid for by the facility or the resident and are administered by the facility staff or outside agencies (NCAL, 2001).

Most states specifically regulate and differentiate between medication assistance and medication administration in ALFs. Twenty-four states permit medication administration by unlicensed staff members under the supervision (and in some cases, instruction) of a physician, RN, or pharmacist. In some states, this is permitted through regulation; in others, it is under the state board of nursing jurisdiction, but most commonly it is authorized by ALF policies. Delegation is rarely authorized by state nurse practice acts. State regulations are less specific with regard to treatment administration. For example, oxygen or enteral feeding must be self-administered by the resident as a condition of retention in ALFs in some states. It is unclear whether and how residents or the staff administer and monitor control of opioid medications; the regulations are silent on this.

In many, but by no means all, states, ALF residents’ weights are monitored. Few states permit ALFs to offer enteral feeding, IV, or clysis. Of those, the ALF or resident must arrange for provision and supervision of this skilled nursing/medical service.

Advance Directives.—We found no study that addressed the prevalence of advance directives in ALFs or of the relationship between advance directives and transfer to the hospital from an ALF for residents at the end of life. Only a handful of states require that ALF residents be informed about their right to create an advance directive. Some states specify that a copy of any directive be placed in the resident’s record, but most states are silent in this regard. A few states specify that a DNR or CPR order must be on record as a condition of admission or retention. However, honoring a DNR directive becomes ambiguous in states that do not permit a professional nurse in the ALF to pronounce death; the staff must continue resuscitation efforts until an emergency medical services technician or physician arrives. One state does not permit admission of a resident with an active health care proxy (HCP) to an ALF. It is unclear whether a resident can remain in the ALF once an HCP is triggered.

Hospice.—Virtually all states permit, indeed encourage, ALFs to offer end-of-life care provided by a certified hospice agency. There are no reliable data about the number of older people receiving hospice-managed terminal care in ALFs. Of all hospice patients
age 65 and older, 10% die in board-and-care or residential facilities (Haupt, 1998b), many of which may be ALFs. Regulations are unclear with regard to which nursing tasks a hospice nurse can delegate to the ALF staff. This is particularly vexing in that hospice staff members are reportedly annoyed with the ALF staff for not assuming the primary caregiver role or the 24-7 caregiving required by hospice regulations. We found no data as to how many or how often ALF residents who are receiving hospice care are transferred to a hospital when death is imminent.

Medicare is the primary payer for hospice care, although many states have a Medicaid hospice benefit for Medicaid beneficiaries that is also applicable in ALFs. Residents who are not Medicare hospice eligible can privately purchase hospice care if their care needs are deemed to be consistent with facility and/or state regulations.

Hospital Transfer. — There is some evidence (Chapin & Dobbs-Kepper, 2001) that ALFs try to forestall the transfer of private pay residents to either acute care hospitals or an SNF even when their health and levels of ADLs deteriorate below the levels they accept for admission. We found no data regarding the transfer to the hospital of ALF residents at the end of life. There is some anecdotal evidence of the high use of transfers to the emergency department (ED) of ALF residents. One study (Phillips et al., 2000) found that ALFs with no full-time RN were more likely to discharge residents to an SNF than ALFs with a full-time RN.

Facility Policies and Staffing. — Of states with tiered Medicaid rates for ALFs, no state has a special end-of-life care rate. Four states require ALFs to provide staff education about death and dying (Mollica, 1998). Six states require that staffs be educated about the Patient Self-Determination Act. Fifteen states require education about normal age-related changes, monitoring and reporting changes in physical condition, behavior or mentation, medication effect, communication issues, and the Heimlich maneuver. Almost all states require education about safety, infection control, resident rights, CPR, and first aid (NCAL, 2001).

Facilities employ or contract with professional and nonprofessional staff, varying by state, number of residents, and their service requirements. Survey data indicate that no physicians are employed by or are on contract to an ALF. Data as to the number of ALFs with licensed nursing staff members [RNs and licensed practical nurses (LPNs)] vary from 55% (Hawes et al., 1999) to 40% (NCAL, 2001). When asked whether their facilities would provide nursing care, 54% of ALFs indicated that they would provide care using their own staff, 25% would arrange care, and 21% would neither provide nor arrange care (Phillips et al., 2000). One study (Phillips et al., 2000) found that for-profit ALF residents were more likely to be transferred to a setting other than an SNF.

Residents can privately arrange for or purchase additional LPNs or personal care staff members as is commonly done—and often required by regulation—during an acute episode or period of instability or during the provision of hospice care. The number of staff members required to be awake on the premise varies broadly among states. Anecdotal information indicates that some ALFs have a nurse practitioner (NP) on staff; in some cases, the NP is shared with an SNF or a CCRC. Several states indicate, however, that a resident’s primary care provider can be an NP with full authorization to determine resident appropriateness for ALF residency.

SNFs

Overview

Overall, 20% of deaths in the United States occur in SNFs (Happ et al., 1999). The mortality rate for SNFs is estimated to be 25% annually (Zimmerman et al., 2001). Older people who die in SNFs are primarily characterized by a dying trajectory of frailty, with 60% having a diagnosis of either stroke (50%) or hip fracture (11%; Lunney et al., 2002). Between 50% and 60% of all deaths in SNFs are residents who have a diagnosis of dementia (Magaziner et al., 2000; Travis et al., 2001). Of Lunney and colleagues (2002) frail category of decedents, 75% of those with dementia or Alzheimer’s disease were older than the age of 80, and 80% had billing indicating that they had spent some time in an SNF in the year before death. It is estimated that, by the year 2040, 40% of all deaths will occur in SNFs (Teno, 1998).

Of the more than 1.5 million people who reside in the nation’s more than 15,600 SNFs, 90% are age 65 and older, and 50% are 85 and older. SNFs are typically for profit (65%) and have an average size of 102 beds (Harrington, Carrillo, & Wellin, 2001). Residents nationally have more than three deficits in ADLs, 58% evidence cognitive impairments, and 61% report three or more chronic conditions (Harrington et al., 2001). The average length of stay of residents in SNFs is 870 days from time of admission (Gabriel, 2000). Approximately half of SNF residents are admitted for short, “subacute” care, typically after hospitalization for a hip fracture or stroke. Twenty-four percent of all hospice recipients reside in SNFs (Miller, Gozalo, & Mor, 2000).

It is important to keep in mind that SNFs do not see themselves as primarily caring for the dying. Rather, the customary goal of care in SNFs has been to maximize the independence and functionality of residents to the highest level of attainment. The focus of care is on routines of daily care and routines of daily life. SNFs still do not generally have a physician or NP in the facility, and they generally transfer residents to the hospital for conditions requiring medical management.

Quality of care at the end of life and quality of dying for SNF residents who have dementia raise special concerns. Because many persons with dementia are unable to report symptoms or make their wishes known, their symptoms are generally underreported.
and undertreated. With the exception of Volicer and colleagues' (Volicer & Bloom-Charette, 1999; Volicer, Harley, Lathi, & Kowell, 1994) work, which shows promise in developing outcome measures to assess quality care for dying older people with Alzheimer’s disease and dementia, we lack the moral, legal, and ethical consensus as to when someone with dementia has begun the dying process or how to manage symptoms related to pain and nutritional status in persons with dementia. There is growing acceptance, however, that when assisted feeding is no longer able to sustain nutritional needs, the dying process is under way. SNFs are unclear as to when, and under what conditions, persons with dementia will benefit from transfer to a hospital. In some SNFs, lacking an advance directive, terminally ill, frail residents with dementia spend their last days receiving aggressive but futile care in hospital intensive care units. In other facilities, dying residents with dementia are not automatically transferred to a hospital, even when such a transfer might yield palliative treatment that would improve their quality of life (Miller, Longino, Anderson, James, & Worley, 1999). Finally, SNF residents with dementia are rarely referred to hospice.

State of Science

Pain and Symptom Management.—The issue of pain management in SNFs reflects the overall concerns related to dying older adults discussed under home care. There are, however, some unique aspects of pain management that are particularly common in SNFs. Nationally, the prevalence rate of pain among residents of SNFs varies widely: for example, 17% (Teno, 1998), 26%–66% (Fried, van Doorn, et al., 1999), and 41% (Teno, Weitzen, Wettle, & Mor, 2001). The true prevalence rate is difficult to estimate because of the inadequacy of instruments to assess pain in cognitively impaired older adults (Parmelee, 1996). Typical methods to approximate pain levels in severely cognitively impaired older adults include observations of resident pain (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992), family and staff perceptions of pain (Weiner, Peterson, & Keefe, 1999), and assumptions of pain that are based on pain reports in cognitively intact older persons (Miller et al., 1996). All of these methods lack sufficient validity and reliability to be used with clinical assurance in assessing pain in cognitively impaired persons (Herr & Mobily, 1993). We found no study that examined the prevalence of pain in dying SNF residents. One national study documented that 1 in 5 SNF residents with a diagnosis of cancer reported pain that was untreated (Teno, 1998). Unfortunately, failure to describe the type of cancer or recency of diagnosis limits the generalizability of this study. Finally, in the current climate, administrators in SNFs fear litigation and regulation for older people who are both undermedicated and overmedicated.

Several studies have addressed the nutritional status of dying SNF residents. Kayser-Jones (1999), using a qualitative design, reported that 93% of dying residents had a body mass index lower than 23 and that inadequate staffing played a large role in malnutrition. However, Zerwekh (1997) has indicated that nutritional deficits and dehydration in SNF residents are compatible with quality of life at the end of life. Lunney and colleagues (2002) found that 53% of elderly Medicare decedents classified in the frail category had a diagnosis of dehydration at the time of death. Anecdotal data suggest that facilities lack clarity as to their obligations and options in offering nutrition and hydration to dying residents.

As stated previously, nutrition and hydration continue to be one of the most morally and clinically complex and troubling areas of the process of care for dying persons. Documenting severe nutritional deficits in dying SNF residents, some investigators (e.g., Kayser-Jones, 1999) argue that failure to maintain nutritional status constitutes a form of neglect and abuse. On the other hand, others (Lunney et al., 2002; McCann, Hall, & Groth-Juncker, 1994) argue that failure to take food and fluids is a normal component of the dying process and that a certain degree of cachexia is inevitable as people approach death. In SNFs, where maintaining adequate weight is a goal of care, regulations regarding standards of care for acceptable weight loss and hydration status (resident assessment profiles) clash with the inevitable decline in nutritional status that occurs as many residents approach death.

We found no studies that explored management of dyspnea in residents dying in SNFs.

Advance Directives and DNR Orders.—Although the literature on advance directives [durable power of attorney for health (HCPs) and living wills] has raised questions as to the overall usefulness of these documents (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991), in SNFs there is substantial evidence to support their efficacy in promoting quality of care at the end of life and in limiting unwanted or unnecessary transfer of dying residents to the hospital (Cohen-Mansfield et al., 1991). It appears possible to achieve high levels of advance directives and DNR orders in SNFs (Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000; Tolle et al., 1999). In one study in Oregon, SNFs achieved 67% advance directives and 91% DNR orders (Tolle et al., 1999). When protocols are used to determine what residents want in terms of end-of-life care, the percentages of transfers and hospital deaths of residents at the end of life decrease markedly (Tolle et al., 1999; Travis et al., 2001). A small number of SNFs have developed advance directives that stipulate “comfort care” or “palliative care,” and an even smaller number (4%) allow residents and proxy to sign a “do-not-hospitalize” directive (Mezey et al., 2000). Despite an advance directive for comfort care only, there is some evidence that transfers occur when families are unable to “stay the course” in terms of their decision (Travis et al., 2001) and request that their relative be transferred to the hospital. Also problematic are the large number of SNF residents with cognitive impairment who have
Hospice.—Nationally, 11% of all Medicare-reimbursed hospice care is delivered in SNFs (Miller et al., 2000). Families believe that hospice care of SNF residents improves quality of care and reduces unnecessary hospitalization (Baer & Hanson, 2000). There is some objective evidence to support these impressions. SNF residents who receive hospice care have fewer hospitalizations than similar residents not cared for by hospice (Miller et al., 2000). Moreover, SNFs where hospice is providing care have lower hospitalization rates for dying residents, irrespective of whether they are receiving hospice services, perhaps reflective of diffusion of a hospice philosophy throughout the facility (Miller et al., 1999). In addition, there is some evidence (Travis et al., 2001) to support that hospitalization of SNF residents precedes a hospice referral, suggesting that a hospitalization may help the family and staff accept that a resident is on a dying trajectory.

Despite strong evidence that supports quality of life for older people receiving hospice services, powerful and not fully understood forces continue to limit appropriate referral to hospice for frail SNF residents at the end of life. Anecdotal data suggest that SNF acceptance of hospice is regional, with many hospice referrals in some states and regions and virtually none in others. The reasons for these regional discrepancies are unclear. Cancer is the predominant diagnosis of SNF residents enrolled in Medicare hospice programs (NHPCO, 2001); dementia and cardiovascular diseases are underrepresented as the primary diagnosis for SNF hospice recipients. Currently, only 2% of all hospice patients nationwide have a diagnosis of dementia (Haupt, 1998b), but efforts to improve the prognostication of death in persons with dementia (Luchins, Hanrahan, & Murphy, 1997) may help increase the hospice referrals of dying SNF residents. Many SNFs indicate that they do not refer residents to hospice because they already provide palliative care equal to or better than hospice. One study, however (Travis et al., 2001), found that such palliative care is not timely, is interrupted by aggressive acute care, and is often delayed until the last few days of life.

Differing interpretations of Medicare regulations by fiscal intermediaries have left SNF administrators apprehensive about the eligibility of their residents for hospice services. The Medicare hospice benefit does not reimburse for the high level of personal care needed by most SNF residents (Meier & Morrison, 1999). Almost all hospices reimburse SNFs the same or more than Medicaid would pay if the resident had not elected hospice (Petrisek & Mor, 1999). Of six hospices that paid more than 100% of the Medicaid daily rate, the hospice had a higher percentage of residents enrolled (Office of the Inspector General, 1997). Moreover, SNFs and hospice both benefit financially from having Medicaid-reimbursed hospice residents; the facility benefits from additional staff hours at no additional costs, increased census, and reduced supplies and medication costs because these are supplied by hospice (Office of the Inspector General, 1997). On the other hand, Medicaid payment rates in some states are too low to enable hospice agencies to provide state-of-the-art pain relief. Some states require older people to relinquish home and community services when they opt for hospice (Tilly & Wiener, 2001).

Hospital Transfer.—Transfer or relocation trauma is a well-recognized phenomenon in SNFs, resulting in sudden death, disorientation, mood change, and so forth (Creditor, 1993). Although the trauma of transferring dying residents to the hospital has received scant study, the consequences of transfer of SNF residents to the hospital at the end of life has generated increased research attention over the past 5 years.

Accurate transfer rates of dying residents are not available. Nationally, annual transfer rates from SNFs to hospitals range from 17% (Brooks, Warshaw, Hasse, & Kues, 1994) to 34% (Mor, 1998). When transferred, approximately 15% of residents are seen in the ED and returned to the SNF, 84% are admitted and then return to the SNF, and 12% die in the hospital (Murmaugh & Freiman, 1995). Studies suggest that between 40% and 50% of transfers are unnecessary (Saliba et al., 2000). Twenty percent of transfers are for treatment of infections that can be treated equally well in the SNF (Gilllick, Berkman, & Cullen, 1999). SNF residents who are transferred to the hospital make up 8.5% of all Medicare ≥65 hospital admissions (Murmaugh & Freiman, 1995). They are thought to account for 2 million unnecessary hospital days (Teresi, Holmes, Bloom, Monaco, & Rosen, 1991). Treatment of upper respiratory and urinary tract infections of SNF residents in the hospital is thought to cost $1 billion (Brooks et al., 1994).

There is strong evidence that health care service issues—such as hospital occupancy rate, regulations, and reimbursement—exert a powerful influence on the transfer of residents from SNFs to acute care hospitals. Miller and coworkers (2000) documented that the hospital occupancy rate has an inverse and direct relationship to transfer of SNF residents to the hospital. The more hospital beds in a geographical region, the greater the number of in-hospital deaths (Mor, 1998). Patients are seven times as likely to die in the hospital in the region with the most hospitalization versus the least (Covinsky et al., 1994). Interestingly, administrative and professional staff members in SNFs deny that hospital occupancy rates influence the transfer of residents from SNFs to the hospital.

The state survey process also exerts a powerful effect on transfers generally. Surveyors have traditionally viewed the increased number of deaths in an SNF as a marker of poor care, warranting heightened regulatory oversight. SNFs that offer palliative care or fail to transfer dying residents worry that they will be sanctioned for inadequate care of residents (Mezey & Dubler, 2001; Travis et al., 2001).
Overall, both Medicare and Medicaid reimbursements favor hospitalization for the medical management of dying SNF residents. Because SNF residents who receive Medicaid are “dually insured,” Medicare pays a significant portion of the medical costs of SNF residents (e.g., physician services, durable medical equipment, ambulance transfer). Medicare reimburses physicians more to see an SNF resident in the ED or the hospital than in the SNF, providing a powerful incentive to transfer. On the other hand, fully capitated Medicare models of care, such as Evercare, that employ NPs to be on-site in the facility, have been shown to significantly improve care in the facility and also to reduce transfers of residents to the hospital.

Being discharged from the SNF to the hospital to die is almost always provider-initiated and in one state (Oregon) was found to be associated with diminished survivor and/or family satisfaction (Tolle et al., 1999). Because they lack on-site physicians or nurse practitioners, SNFs are dependent on off-site coverage for medical management of residents. In a single-site study of dying residents, Travis and colleagues (2001) found that there is a greater likelihood of transfer if the resident’s regular physician is away or cannot be reached. In studies that look at transfer generally, when a physician is not present and has to be called to discuss the deteriorating health of a resident, in 48% of cases the resident is transferred to the ED or admitted to the hospital (Saliba et al., 2000). An expert panel viewed 36% of these ED transfers and 40% of the hospital transfers to be inappropriate (Saliba et al., 2000). On the other hand, immediate access to a physician or nurse practitioner appears to decrease hospital transfers. Reinhard and Stone (2001) and Ryan (1999), among others, have shown significant reductions in transfers to the hospital when NPs are on-site to manage frail residents.

Studies have shown that certain diagnoses commonly seen in dying residents, for example, pneumonia, can be equally well managed in the SNF compared with the hospital (Fried, Gillick, & Lipsitz, 1997). Limiting the transfer of dying residents with pneumonia might substantially cut down on transfers. Lunney and colleagues, for example, found that 44% of frail SNF residents who died had a diagnosis of pneumonia. Travis and coworkers (2001) report that 25% of residents had a diagnosis of pneumonia in the year before death. The number of these residents who were transferred to the hospital prior to death is unknown.

Oregon has experimented with interdisciplinary team planning and implementation of instruments such as the physician’s order for life-sustaining treatment for SNF residents at the end of life (Tolle et al., 1999). In Oregon, 35% of deaths occur in hospitals compared with the national average of 56%; the relationship of this lower death rate to protocols and team planning is speculative. Mulvihill, Dubler, Post, and Mitty are testing an algorithm for determining the appropriateness of transfers that shows promise in reducing unnecessary resident transfer to the hospital (as cited in Post & Mitty, 2001).

Facility Policies and Staffing.—Beyond the knowledge and skills of individual providers and the adherence to regulatory oversight, SNFs have a facility-level responsibility in ensuring quality at the end of life (Mezey et al., 2001). These include establishing a mission statement and policies and procedures that foster quality of care for the dying and quality of the dying process.

Although nurse staffing patterns are known to affect quality of care in SNFs, the impact of staffing patterns on care at the end of life or quality of dying has not been studied. The median staffing in SNFs is .59 hr per resident per RN, .67 hr per resident per LPN per 24 hr, and 2.14 hr per certified nursing assistant (Harrington, Zimmerman, Karon, Robinson, & Beutel, 2000). Currently, close to 50% of SNFs nationally do not have an RN in the facility 24 hr a day. Very few SNFs have a physician on staff and in the facility 12 hr a day. Some have an NP, although the number of residents who receive care from an NP is unknown.

Low professional nurse staffing and poorly trained nonprofessional staff members have been cited as contributing to poor quality of care by residents, families, and federal and state oversight agencies (Feldt, 2000; Harrington et al., 2000; Kovner, Mezey, & Harrington, 2000) and are associated with more transfers of residents to the hospital (Engle et al., 1998). There is some evidence that palliative care teams improve quality of dying and limit the transfer of SNF residents at the end of life.

Prison Facilities

Overview

Prisons represent a small, yet fast-growing setting for end-of-life care of older adults. In 2000, there were more than 2 million federal, state, and local prisoners in the United States (Stevens, 2001). Of those in federal or state prison, 1.4% are age 65 or older, and another 4.3% are age 56–65 (U.S. Department of Justice, 2001). Between 1995 and 2000 the percentage of federal prisoners age 65 years and older increased by 73% (U.S. Department of Justice, 2001).

The aging of prisoners is largely from the change in sentencing laws that require long sentences to drug-related offenses and generic laws, such as “mandatory minimums” and “three strikes and you’re out” (Cohn, 1999). In addition, because of the conditions in which prisoners are forced to live, they tend to age physiologically more quickly than people living freely outside the constructs of a prison. This “aging” can add 10 years to the life of a 50-year-old prisoner (Cohn, 1999).

In contrast to the demographics of the nation as a whole, federal prisoners are disproportionately men (93%) and primarily minority (only 29% are non-Hispanic Whites; Grieco & Cassidy, 2001; U.S. Department of Justice, 2001). State prison populations are similarly disproportionate, with only 6% of inmates women and only 33% non-Hispanic Whites (U.S. Department of Justice, 2001).
Unlike the varying degrees of choice of care for most older people at the end of life, prisoners are limited to what the correctional system offers. Generally, a prison has a small medical unit in which minor injuries and illnesses can be handled without requiring the transfer of the patient to another facility. In addition, a small but growing number of prisons and prison systems are developing a hospice setting for dying prisoners (Dubler, 1998). Prison systems also have contracts with or a division within an acute care facility for the care of more major injuries and illnesses.

Unlike the other settings discussed in this article, the goals of care in prisons are not the only stimuli for how the recovery is treated and which patient needs are met. Permissible and appropriate goals of care for dying patients vary from system to system, prison to prison, and prisoner to prisoner, depending on the types of care available and the philosophy of the ward, corrections officers, supervisors, and other corrections administrators. The goal of care is quite often not aligned with what the prisoner wishes but what is best for smooth prison administration. The U.S. Supreme Court has ruled that prisoners can be ordered to undergo treatment that they might otherwise refuse if the prison administration views the forgoing of treatment as damaging to the prison community, as long as the “treatment is in the inmate’s best medical interest,” a fact determined mainly by administrative and not medical personnel despite the fact that the Supreme Court has ruled that prisoners have a constitutional right to medical care (Washington v. Harper, 1989).

No prison system has achieved the goal of “patient-centered care,” as this is inimical to corrections philosophies and systems. However, the question then arises of who decides what is in the inmate’s best interest? What if a warden decides that the state has a “legitimate penological interest” in treating an inmate who is competent and wishes to forgo treatment at the end of life that would only extend the prisoner’s life for a short amount of time (Parker & Paine, 1999)? The goal of medicine is to diagnose, comfort, and cure; the goal of corrections facilities is to confine and punish. These are mutually exclusive goals that exist in an uneasy alliance in the best systems and succumb to scrutinized emotional and medical neglect in the worst facilities. The health care team in general has a negative attitude toward patients in such facilities. One survey of prison facility nurses showed that, even though they are working with inmate patients, nurses maintained a negative attitude toward them (Shields & de Moya, 1997).

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Pain and Symptom Management. — Overall, pain management is dealt with quite poorly in the prison setting (Dubler, 1998). This is because of the inability of prison physicians to properly medicate because of the lack of analgesics allowed to be brought into the facility (Dubler, 1998). Pain management is even less well managed if a patient has a history of drug abuse (Dubler, 1998). Patients with prior drug abuse tend to be disbelieved when they say they are in pain, even if they have a progressive chronic disease (Dubler, 1998).

Nutrition and hydration are just as difficult as pain management for the prison medical staff to tackle. Restrictions on food availability lead to substantial difficulty in providing meals with the correct nutritional value for a given condition (Dubler, 1998). Prison kitchens are hard pressed to provide special meals to prison inmates and often do not have the resources, time flexibility, or inclination to provide for special dietary needs. Beyond the lack of specialization for dying prisoners, there are very few standards followed by the entire prison system for nutrition and hydration.

Advance Directives and DNR Orders. — Although advance directives are an integral part of the management of terminal care, executing a directive in a prison setting is difficult. Both a living will and HCP can legally be executed in the prison setting, but they will not necessarily be followed if issues of smooth administration run counter to the patient’s wishes. An HCP, the more preferable of the two directives, requires a proxy to be available on-site or on call to make decisions regarding health care decisions at the end of life. This can be problematic for several reasons, the most substantial of which is that regulations regarding visits tend to be extremely limiting; many inmates are estranged from families, and prison administrators are unlikely to permit inmates to act as health care agents for other inmates (Dubler, 1998). In addition, prisons often refer dying inmates to hospice well before all advance measures have been attempted, making a correctable condition into an uncorrectable one. This makes a proxy document and HCPs themselves very important, because HCPs can push for more aggressive treatment where it might not occur otherwise (Dubler, 1998). The Volunteers of America G.R.A.C.E. Project (Schmidt, 2000) is developing standards that strongly encourage advance care planning in jails and prisons.

Hospice. — Prison systems have begun to create hospice units to handle the increasing number of deaths from chronic illness. These units are generally referred to as designated death units (DDUs), and if a system has one, patients from all different facilities in a system (state) will be sent there to die (Dubler, 1998). The idea behind the DDU is that the doctors and staff could be trained to deal with end-of-life care specifically, thus improving the quality of death. Although this innovative form of health care could be seen as a positive step in the end-of-life process, it has actually become damaging, because many inmate patients are transferred to the facility in lieu of aggressive treatment for possibly curable problems (Dubler, 1998). Another problem stemming from the DDU is
that it is often not at the prison where an inmate is being held, thus the inmate must be transferred away from family and friends to another location, where the inmate becomes less accessible. This transferring can lead to dying alone, which would lower rather than raise the quality of death.

**Hospital Transfer.**—Although they are more difficult to execute, advance directives are especially important for the inmate, because they can prevent unnecessary hospital transfer at the end of life. When inmates are transferred to a hospital from a prison facility, they are required to be handcuffed, which for dying residents is a cruel injustice. They will also be removed from what few friends they had in the prison system and will be faced with new doctors and nurses (Dubler, 1998).

**Facility Policies and Staffing.**—Access to health care in the prison system is limited in several ways. The first and foremost way in which health care is limited is the prison guard. Prison guards control the access of prisoners to health services, and thus denial of care by the guard and refusal of care by the inmate can become impossible to distinguish: A patient’s not showing up could be caused by either, and the medical team would never know by which (Dubler, 1998). In addition, when looking at access, we must look at the quality of care provided, because generally a minimum amount of care is provided for prisoners, and decisions to limit care are not always based on whether a full range of efforts has been afforded the prisoner (Ornduff, 1996).

Visitation within prisons is limited to begin with; however, within the medical portion of the institution, visitation is limited even further (Dubler, 1998). The limitation wavers between institutions; however, it can include family, clergy, and other prisoners, thus making the patient’s quality of dying significantly lower than in a facility with fewer restrictions (Dubler, 1998). Without familial or spiritual support, it can be difficult for a prisoner to die with dignity and can prevent the patient’s wishes from being respected. Several prisons have created programs in which inmate volunteers are trained to care for their fellow dying inmates (Cohn, 1999).

Compassionate release programs provide enfeebled inmates a chance to live what little life is left outside of a prison, by means of medical parole. Although this program can be seen as a blessing for a patient, as the inmate would not have to die within the confines of a prison, it can be riddled with questions such as where will the inmate obtain end-of-life treatment, how will the inmate pay for medical services, and what incentives does the parole board have for releasing an inmate on these grounds (Mahon, 1999)? For a compassionate release program to be successful, these questions and others must be answered. A partial answer is to provide medical discharge planning to inmates who are given medical parole (Mahon, 1999).

### Research Needs: Impact of Setting and Transitions on Quality of Life at the End of Life and the Quality of the Dying Process

In this section of the article, we begin by identifying the research needs regarding quality of life and quality of the dying process for older adults across settings (homes, ALFs, SNFs, and, where appropriate, prisons). Where comparative studies are proposed, we suggest that comparisons be made to care in hospitals, where most deaths occur. We next address the research needs specific to each setting. In identifying research needs, we have tried to address broad areas that have a high likelihood of yielding useful data for clinical practice and public policy.

#### Research Needs Across Settings

Qualitative studies are needed of older people and family expectations about quality of life at the end of life and quality of the dying process, especially for the very old. Of particular importance are studies of cultural and ethnic expectations about quality of life and quality of the dying process. We suggest, further, that studies examine the trajectories of dying as proposed by Lunney, Lynn, and Hogan (2002).

Clinical research should include the development of measures to assess pain for older people with cognitive impairments and to determine the extent to which symptom management varies in effectiveness across settings. We propose that clinical trials could help establish the efficacy across settings of standards of care for symptom management (e.g., dyspnea), standards of care for nutritional management, the impact of pharmacy services on adequacy of pain management across settings, and outcomes of hospice and palliative care models (comfort care) across settings.

In relationship to hospital transfers, qualitative studies are needed to identify the factors that trigger family members to change their minds about the type and site of care at the end of life.

No discussion of research needs of end-of-life care would be complete without attending to the influence of staff and staffing patterns on quality. Clinical trials are needed to determine outcomes of staff qualifications, availability and staffing patterns on quality of end-of-life care, quality of dying, and hospital transfer across settings. In addition, clinical trials are needed to determine outcomes of palliative care teams on quality of end of life care, quality of dying, and hospital transfer across settings.

#### Setting Specific Research Needs

Given the projected increase in the number of individuals who will be choosing to die at home, clinical trials are needed to determine the effectiveness of advance directives (HCPs, community-based DNRs) on the quality of care at the end of life, quality of dying, and hospital transfer. Similarly, as more older adults choose or are guided toward assisted living residence (ALFs), more deaths will occur in ALFs. Inasmuch as
there are two revenue streams in assisted living—Medicaid and private pay—studies are needed to examine the impact of source of payment on the quality of care at the end of life and quality of dying in ALFs.

With regard to SNFs, although there is strong evidence that NPs improve outcomes for residents in these facilities, clinical trials are needed to determine outcomes of NP models on the quality of end-of-life care, quality of dying, and hospital transfer. Given the efficacy of the POLST in improving quality end-of-life care and quality of dying in SNFs in Oregon (Tolle et al., 1999), clinical trials are needed to determine ways to promote the use of advance directives (e.g., HCP, Five Wishes, POLST) in SNFs nationally. Finally, we see the need for studies to clarify discrepancies between health services research and SNF staff perceptions as to the influence of hospital occupancy rates on transfer decisions.

In relationship to hospice, clinical trials are needed to promote enrollment, examine length of stay, and evaluate quality of end-of-life care and quality of dying of older people with primary diagnoses of dementia and cardiovascular disease. Clinical trials are warranted to determine outcomes of hospice and palliative care models (comfort care) across settings.

This review demonstrates the imperative for research to identify and suggest ways of addressing the needs of dying patients in nonhospital settings. Such studies are extremely difficult to design and pursue, given that many patients involved have fluctuating, diminished, or absent decisional capacity. Thus, the participants may not be able to provide legally and ethically adequate informed consent. The lack of agreement regarding appropriate standards for enrolling these patients has proved a substantial barrier to this research. Therefore, we recommend that the National Institutes of Health convene a working group to examine how Federal regulations may be rewritten or reinterpreted to facilitate this research on quality end-of-life care.

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