Preference for Place of Death in a Continuing Care Retirement Community

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Purpose: To describe death-related planning and preferences for place of death among well elders in a community characterized by a low rate of hospital deaths. Design and Methods: Cross-sectional prevalence survey of independent-living residents (n = 219) of a continuing-care retirement community (CCRC) in Central North Carolina characterized by a low rate of hospital deaths. Results: Death-related planning played a part in the decision of 40% of residents to move to the CCRC. A majority of residents reported a clear preference for place of death, and a majority of these preferred to die on the CCRC campus. Most residents wanted to discuss their preferences for place of death with their health care provider. Preferences for place of death appear consistent across age cohorts and are relevant to elders' long-term care decisions. Implications: Given the striking discrepancy between patient preferences and outcomes has been reported for other end-of-life issues (Danis et al., 1996; Hakim et al., 1996; Teno, Lynn, et al., 1997). The widespread perception that institutional factors routinely override the preferences of dying patients has renewed interest in the causal web of place of death (Chin, Hedberg, Higginson, & Fleming, 1999; Coulehan, 1997; Donaldson & Field, 1998; Meier, Morrison, & Cassel, 1997; Morrison, Meier, 3 Cassel, 1996; Teno, Branco, et al., 1997; Dartmouth Medical School, Center for the Evaluative Clinical Sciences, 1998).

Although affected slightly by patient preferences, place of death is subject to demographic and clinical factors, with lower odds of hospital death among White and married patients and those with specific diagnoses (e.g., cancer; Fried, Pollack, Drickamer, & Tinetti, 1999; Pritchard et al., 1998). However, geographic region of the United States—likely acting as a proxy variable for structural features of local health systems, such as bed availability and access to nursing homes and hospice services—appears to be the most powerful predictor of place of death (Pritchard et al., 1998; Tolle, Rosenfeld, Tilden, & Park, 1999; Zusman & Tschetter, 1984). Nearly three-quarters of U.S. deaths take place in institutions (57% in hospitals, 17% in nursing homes) with the remaining 20% at home and 6% elsewhere (Institute of Medicine, 1997). The striking discrepancy between patient preferences and outcomes has been reported for other end-of-life issues (Danis et al., 1996; Hakim et al., 1996; Teno, Lynn, et al., 1997). The widespread perception that institutional factors routinely override the preferences of dying patients has renewed interest in the causal web of place of death (Chin, Hedberg, Higginson, & Fleming, 1999; Coulehan, 1997; Donaldson & Field, 1998; Meier, Morrison, & Cassel, 1997; Morrison, Meier, 3 Cassel, 1996; Teno, Branco, et al., 1997; Dartmouth Medical School, Center for the Evaluative Clinical Sciences, 1998).

Most patients in the United States would prefer to die at home, when in fact most die in acute care hospitals (American Health Decisions, 1997; Groth-Junker & McCusker, 1983; Institute of Medicine, 1997; McCusker, 1984; Pritchard et al., 1998; Tolle, Rosenfeld, Tilden, & Park, 1999; Zusman & Tschetter, 1984). Nearly three-quarters of U.S. deaths take place in institutions (57% in hospitals, 17% in nursing homes) with the remaining 20% at home and 6% elsewhere (Institute of Medicine, 1997). The striking discrepancy between patient preferences and outcomes has been reported for other end-of-life issues (Danis et al., 1996; Hakim et al., 1996; Teno, Lynn, et al., 1997). The widespread perception that institutional factors routinely override the preferences of dying patients has renewed interest in the causal web of place of death (Chin, Hedberg, Higginson, & Fleming, 1999; Coulehan, 1997; Donaldson & Field, 1998; Meier, Morrison, & Cassel, 1997; Morrison, Meier, 3 Cassel, 1996; Teno, Branco, et al., 1997; Dartmouth Medical School, Center for the Evaluative Clinical Sciences, 1998).

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CCRCs, or life-care communities, provide housing and services, including health care, to persons of retirement age and are distinguished by the terms of their long-term contracts, the types of accommodations available, and the fee structure (Branch, 1987; Sherwood, Ruchlin, Sherwood, & Morris, 1997; Somers, 1993). A CCRC contract typically assures the lifetime use of an independent-living unit (e.g., cottage or apartment) or a nursing home bed on the CCRC campus, as well as a range of amenities and support services, for a substantial entrance fee and fixed monthly payments. CCRC health care services vary widely. Most offer social services, assisted living units, skilled nursing, and recreational therapy; one-third provide home health care; and one-quarter offer CCRC physician services (Somers & Spears, 1992). Although only 1% of U.S. elders lived in CCRCs in the mid-1990s, it has been estimated that residence in such communities will be affordable for 25% of those aged 75 and older by the year 2020 (Somers, 1993; Somers & Spears, 1992; United States General Accounting Office, 1997).

CCRCs represent one model of voluntary self-insurance against late-life impoverishment as a result of long-term care (LTC) costs. Whether CCRC residents consider end-of-life issues, in addition to LTC issues, during their decision-making process has not been examined (Cohen, Tell, Batten, & Larson, 1988; Gupta & Galanos, 1996; Sherwood et al., 1997). (Indeed, preferences for place of death in other nonclinical, elderly samples have not been well characterized.) If CCRCs generally display elevated odds of nonhospital deaths, and if residents report high preferences for nonhospital deaths, then CCRCs may provide a model not only for securing long-term and terminal care, but also for supporting end-of-life preferences. This descriptive survey was designed to examine death-related motivations to enter a CCRC, current preference for place of death, and importance placed on communication with clinicians about place of death among well elders whose preferences for place of death are unconstrained with respect to cost.

Methods

Design and Sample

We used a cross-sectional prevalence survey design. The sample was drawn from the same CCRC in Durham, North Carolina, studied by Galanos and Sash (1998). The CCRC provides three service levels: (a) independent living units, (b) assisted living units, and (c) a non–Medicare-certified skilled nursing facility (SNF), with no fee differential across levels for residents who enter at the level of independent. Decisions about transfers between levels of care are made by a multidisciplinary health care team; no formalized transfer criteria are utilized. Health care staff include a board-certified geriatrician with admitting privileges to a tertiary care medical center in the community, as well as dentistry, podiatry, gynecology, nursing, and physical and speech therapy; geropsychiatry consultation is also available. Primary care charges are billed to Medicare B. No home health or hospice services are provided to independent living unit residents; hospice consultation is available for SNF residents. The contract does not discriminate between terminal care and other types of care.

On the basis of previous work on preferences for place of death (Hays, Gold, Flint, & Winer, 1999), we developed a brief, anonymous questionnaire that was approved by the Investigation Review Boards of both Duke University Medical Center and the CCRC. We distributed questionnaires to all independent living unit residents of the community. Of 331 surveys distributed, 222 were returned (response rate: 67.1%). Of the 222 returned surveys, 147 were completed by women and 75 by men. This response rate exactly reflected the 1:1.8 male-to-female ratio in the CCRC. We excluded from the study three respondents who completed the questionnaire but did not complete the item on preference for place of death. The effective sample size was n = 219.

Measures

The questionnaire included four death-related items. To assess end-of-life-related decision making, respondents were asked, “Did any issue surrounding death and dying play a role in your decision to move to a CCRC—Yes or No?” To assess preference(s) for place of death, respondents were asked, “Where would you prefer to die—hospital, your apartment or cottage, healthcare facility on the CCRC campus, no preference, or do not know?” To assess the conditionality of the preference, respondents were asked, “If you have a preference, how certain is it—unconditional (no change under any circumstance) or conditional on (check all that apply): symptom control; amount, type, or duration of care needed; concerns about family or costs, and ‘other’ concerns?” To assess current death-related planning, respondents were asked, “How important is it that the medical community address a patient’s preference for place of death—very important, important, somewhat important, or not important?” With the exception of the CCRC decision-making item, all item stems were identical to those used in previous work (Hays et al., 1999); additional response options were added to the stems, based on the CCRC setting, for example, “your cottage or apartment” was substituted for “your home.” Other closed-ended items included age, gender, marital status, years of education, religious affiliation, the importance of religion in the respondent’s daily life, and self-rated health.

Open-ended formats were linked to two items. Respondents who considered death-related issues when choosing a CCRC, and those with a conditional preference for place of death, were asked to “please explain” their responses. The questionnaire concluded with a general request: “Any thoughts or reactions you wish to share are welcome on a separate sheet.”
Analytical Strategy

Descriptive statistics are presented below. Participants who affirmed the importance of discussing preferred place of death with the medical community were compared to those who did not, using the chi-square statistic or Fisher’s Exact Test, as appropriate. Qualitative data were transcribed and grouped into themes independently by two of the authors (JCH/EPF).

Results

Respondents were primarily female (65%) and married (57%); 27% were aged 85 years or older. Most respondents (84%) stated a religious affiliation (primarily Christian Protestant); religion was important in daily life for 58% of the sample. Approximately three quarters of the sample rated their overall health as good or excellent.

Forty percent of respondents (n = 82) reported that issues surrounding death and dying played a role in their decision to move to a CCRC. Those respondents were slightly more likely (p = .09) to rate their overall health as fair or poor versus good or excellent.

Seventy percent of survey respondents expressed at least one preference for place of death (59% with a single preference, and 11% with more than one preference); 20% had no preference, and the remaining 10% did not know. Approximately two thirds of the sample preferred to die on the CCRC campus: 36% in their apartment or cottage; 18% in the CCRC SNF, and 10% in either (Figure 1). Five percent of respondents listed the hospital as the only preferred place of death, and 2% included the hospital among two or more listed preferences. Eighty-nine percent (n = 171) of all preferences for place of death were conditional, and 46% of these listed two or more conditions, including type (77%), amount (76%), or duration (70%) of care; illness symptoms (50%); family concerns (33%); and cost concerns (32%).

Sixty-one percent of respondents rated talking with their health care providers about their preferences for place of death very important; an additional 25% rated this issue somewhat important. Addressing this concern was significantly more important for the oldest residents (p = .04); unmarried residents (p = .05); residents in worse health (p = .03); residents who had a stated preference for place of death (p = .003); residents whose preference was to die on the CCRC campus (p = .08); and residents whose preference for place of death was unconditional (p = .05; Figure 2). Neither gender, religiousness, nor death-related planning prior to entering a CCRC distinguished those who wanted physicians to address “place of death” from those who did not.

Eighty-seven percent (n = 71) of those who reported that death-related issues affected their plans to join a CCRC attached explanatory comments. Five

Figure 1. Responses of continuing-care retirement community (CCRC) residents (n = 219) to the question, “Where would you prefer to die?” R = CCRC residence (apartment or cottage); SNF = CCRC skilled nursing facility; H = hospital.

Figure 2. Importance ascribed to discussion of preference of place of death with members of the medical community among 219 continuing care retirement community (CCRC) residents, by subgroup. A, Gender: Male (M) vs. Female (F), p = .414; B, Age groups: (65–84 years vs. 85+ years), p = .041; C, Marital status: No (not married) vs. Yes (married), p = .086; D, Self-rated health: Excellent (Exc.) or Good vs. Fair or Poor, p = .027; E, Religion important in daily life: (No vs. Yes), p = .839; F, Did death planning play a role in decision to move to CCRC? (No vs. Yes), p = .448; G, Expression of preference for place of death: Any preference (Any) vs. No preference (None) vs. Don’t know (DK); p = .001; H, Preferred place of death among respondents reporting a single preference: CCRC Campus (CCRC) vs. Hospital (Hosp.), p = .077; I, Conditionality of preference for place of death: Unconditional (Uncond.) vs. Conditional (Cond.), p = .048.
themes emerged most prominently: (a) the need for terminal illness care (as distinct from wellness or disability care), (b) concerns about burden on family, (c) concerns about isolation, (d) desire to be near one’s spouse, and (e) lack of proximity to extended family. One respondent wrote, “We wanted care for terminal illness, as we had no family in our previous home.” Several respondents wished to compensate for a perceived shortfall in social resources at the end of life, preferring “to die gracefully and not to be a strain on our children.” Another respondent anticipated an expanding social network at the end of life, and wanted “to be all under one roof with spouse and new friends . . . until death.” Others’ decisions to enter a CCRC were related to friendship bereavements (“All our friends were dying”) or to global ratings of person-place fit (“[This is] a good place to die!”). Thirteen percent (n = 22) of those with a conditional preference for place of death appended additional comments. One respondent who preferred to die in the CCRC SNF added the caveat:

If the final stage is better controlled by the hospital than by the facilities here, it would be better to be ushered out as painlessly as possible. But other things being equal, I know I’ll get TLC [tender loving care] from the staff [at the SNF] and from friends who will be near at hand, and it would not be like dying in the impersonal atmosphere of a hospital.

Respondents who expressed no preference for place of death assigned higher priority to issues of duration or trajectory than to issues of place, for example, “wherever it’s fastest,” or “I don’t care a hoot where I die so long as it is quick, and I’m still active right up to the end.” Others emphasized spiritual considerations, for example, “I’ll die] when God decides my time has come,” or “It’s up to God.”

General comments (n = 106) were written on approximately half of the questionnaires. Many expanded on previous closed-ended responses, for example, the respondent who explained his preference for the SNF over his apartment or cottage: “[I] don’t want my wife to always think of our home as where I died.” Others emphasize communication with physicians, using written documentation: “I have a Living Will, and my wishes are explained in it” and “See medical directive!” One respondent expressed an ongoing openness to the topic: “I would hope and expect to have understanding and cooperation if or when I need assistance in the ‘where, when, and how’ I’m facing at the end of my long and good life.” Another respondent wanted a “discussion [about] burial or cremation as well.” In contrast, two residents who rated such a discussion not important wrote: “My way of handling the thought of death is not to think about it,” and “a premature or aggressive approach to the subject could be emotionally disturbing and lead to depression.”

Discussion

This preliminary examination of preference for place of death has at least three important implications for geriatric practice. First, older Americans living in the community, like their younger counterparts, prefer not to die in hospitals and want to communicate that to their health providers. Second, a sizeable minority of older Americans in CCRCs were influenced not only by concerns for LTC, but also by concerns related to dying and death. Third, in addition to the advantages already documented in the extant literature, CCRCs may represent a model for matching elders’ personal preferences for place of death with actual clinical practice.

Community-based studies of preferences for place of death among U.S. residents are rare. Two studies, which included few elders, reported preferences for a home over a hospital death by ratios on the order of 5:3 among Mexican Americans, 2:1 among African Americans, and 4:1 among Whites and Japanese Americans in Los Angeles, California, and 2:1 in rural North Carolina (Kalish & Reynolds, 1976; Zusman & Tschetter, 1984). Adults sampled more recently in Australia (Ashby & Wakefield, 1993) and Italy (Toscani, Cantoni, DiMola, Mori, Santosoosuo, & Tamburini, 1991) favored home death over hospital death by 3:1. Our preliminary examination expands the evidence to include well elders in their seventh, eighth, and ninth decades and suggests a remarkable stability in preference for home death over hospital death across the age spectra.

Furthermore, these independently living elders placed significant importance on communicating to the clinical guild their preferences for “place of death,” a relatively neglected aspect of patients’ terminal care preferences. Discussions of place-of-death preferences represent an important clinical teaching opportunity. As Kaufman (1998) and others (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Benoliel & Degner, 1995; Fischer, Tulsky, Rose, Siminoff, & Arnold, 1998) have noted, much of what is known about the process of dying and the technologies and services useful in terminal care are not common knowledge. Geriatric practitioners may elicit concerns, confusion, or uncertainties about place of death that could be resolved with information or strategic planning. In previous work, we found that even Stage 4 oncology patients lack information on hospice care, pain management options, respite and home health aide services, and family counseling opportunities (Hayes et al., 1999). In the current study, 62 participants listed “cost” as relevant to their place-of-death preference, in a community where direct costs to residents for the continuum of care are fixed.

Studies of the motivation to enter CCRCs have emphasized access to long-term medical care and guaranteed housing, rather than end-of-life issues (Gupta & Galanos, 1996; Sherwood et al., 1997). We found that end-of-life issues influenced the decisions of nearly half our sample to enter this CCRC. Continuity of care during the terminal phases of illness and across care sites may be an underappreciated benefit of this and other continuous care models, and one which could be better promoted to populations underserved by each of the models of continuing care.
The role of the CCRC as a potential mediator between terminally ill residents and the greater medical culture is not well understood. It has been shown that achieving one’s preference for place of death is more likely when end-of-life issues, such as preparation of an advance directive, are addressed (Institute of Medicine, 1997; Teno, Lynn, et al., 1997; Tolle et al., 1999). In the CCRC described herein, the same physician provides health care on campus, exercises acute-care admitting privileges on behalf of residents, and directs their care during tertiary care hospitalizations. Such provider continuity, including the effective transfer of advance directives across different clinical settings, may have contributed to the low prevalence of deaths in acute care settings in this sample (Galanos & Sash, 1998). CCRCs may also provide particularly effective communication and support of informal caregivers. Physical and emotional exhaustion of family caregivers and patients associated with a prolonged terminal phase is the most frequent reason for institutional deaths among elders who prefer to die at home (Groth-Junker & McCusker, 1983). For families increasingly involved in decision making at the end of a patient’s life, CCRCs provide settings for care that are “known quantities”: chosen and financed in advance of need, clustered in a single setting, staffed by clinicians known not only to the patient, but to the family as well, and thus an acceptable alternative to a high-tech environment.

The findings from this study are highly preliminary and lack generalizability. CCRC residents are more likely to be White, well-educated, and financially secure than their community-dwelling age peers (Sherwood et al., 1997), and the population of this CCRC is typical in these respects. However, it is precisely in such a population—one that is relatively healthy and financially unconstrained—that unbiased preferences are most likely to be elicited. This study was also limited to a single CCRC, and its contract, service levels, and fee structure will differ from other CCRCs. Whether enrollees in any of the patchwork of programs that constitute U.S. health care for elders (e.g., other CCRCs, Program of All-inclusive Care of the Elderly projects [Eng, Pedulla, Eleazer, McCann, & Fox, 1997], or social/health care maintenance organizations [Kane et al., 1997]) or enrollees in more prevalent managed care or fee-for-service practices report similar place-of-death preferences and similar prevalent desires to discuss those preferences with their care provider is a topic of great importance for practice-based research. A recent study of homebound elders in a small community-based, physician-led house call program showed comparable prevalence of planning (64%), prevalence of preferences for home death (5:1), and health status as a predictor of planning (Leff, Kaffenbarger, & Remsburg, 2000). Finally, the cross-sectional design of this survey does not permit estimates of success rates. We cannot be sure that high rates of out-of-hospital deaths among CCRC residents are associated with the resident’s preferences for deaths in the community.

There is reason to hope that the culture surrounding death is changing and that caring professions will embrace end-of-life care as important and possessing its own body of knowledge and skills (Carron, Lynn, & Keaney, 1999; Hammes & Rooney, 1998; Tolle et al., 1999). Given adequate control of symptoms, many older adults wish to die in low-intervention settings. Honoring this preference may be easiest where health systems and policy support specialization in geriatric care and structural linkages across community, long-term, and acute care settings.

References


Received February 11, 2000
Accepted August 28, 2000
Decision Editor: Eleanor S. McConnell, RN, PhD

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