Recent Trends in Advance Directives at Nursing Home Admission and One Year After Admission

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Purpose: Advance directives are important planning and decision-making tools for individuals in nursing homes. Design and Methods: By using the nursing facility Minimum Data Set, we examined the prevalence of advance directives at admission and 12 months post-admission. Results: The prevalence of having any advance directive at admission declined slightly from 2000 to 2004, whereas the prevalence of having any advanced directive at 12 months after admission increased slightly during the same period. Compared with admissions, residents at 12 months post-admission were more likely to have their decisions made by family members and to have advance directives of any type. Implications: The results suggest that greater use of advance directives in nursing homes may depend on additional information and support from nursing facility personnel and the health and social services professionals who are in contact with individuals moving toward nursing home admission, as well as those who remain in facilities over time.

Key Words: Long-term care, Health care decisions, End of life, Late-life long-term care

The Patient Self-Determination Act (PSDA) of 1990 mandated that all nursing facilities receiving Medicare and Medicaid funding provide written information to residents both about their right to reject or accept medical care and about the facility’s policies for implementing their wishes. Since the promulgation of the Act, there has been increasing interest in advance directives among nursing home residents (McAuley & Travis, 2003). Although there was an apparent increase in the use of advance directives by nursing home residents immediately following the passage of the PSDA (Darr, 1999), more recent data suggest that use may be leveling off, with approximately 60% of the current nursing home population having some form of advance directive (cf., McAuley & Travis; Teno et al., 1997). With rare exceptions (Buchanan, Bolin, Wang, Zhu, & Kim, 2004), studies of recent trends in advance directives among nursing home residents have typically used small local, state, or regional data sets.

This research brief uses complete national nursing home Minimum Data Set (MDS) information to present current trends in the prevalence of advance directives at admission and 12 months after admission. Assessments of these recent trends bring into focus how directives are currently being used and suggest topics for additional research that will more fully address late-life long-term care (McAuley & Travis, 2003) as it occurs in nursing
homes. Late-life long-term care is a term that describes two distinct populations. The first, terminal decline, consists of individuals who (a) are recipients of formal or informal long-term care, (b) can be expected to remain in some form of long-term care for the remainder of their lives, and (c) have commenced a trajectory toward end-stage disease. The second late-life long-term care population, terminal admission, consists of individuals who begin to receive long-term care in conjunction with a terminal illness (Travis & Larsen, 2004; Travis, Moore, Larsen, & Turner, 2005).

There are many types of possible advance directives for health care in long-term care. Some researchers have focused on one directive, such as do-not-resuscitate orders (DNRs; Kellogg & Ramos, 1995; Mark, Bahr, Dutchie, & Tresch, 1995), and others have considered multiple advance directives commonly found in long-term care (Cohen-Mansfield, Libin, & Lipson, 2003; Levin et al., 1999; Suri, Egleston, Brody, & Rudberg, 1999). We believe there is value in establishing two conceptually different categories of advance directives in long-term care, based on the specificity of the assessment of treatment futility and immediacy of the directive’s impact on the course of treatment (McAuley & Travis, 2003). Within this framework, basic advance directives are those triggered by generalized knowledge about the likely course of the resident’s condition and have no immediate impact or have limited impact on current care received by the resident. Progressive advance directives, which tend to be less common (McAuley & Travis), are based on a person-specific futility assessment and generally have a direct and/or relatively immediate impact on the resident’s clinical course of care. In this investigation, we organized the advance directives available through the MDS into these two categories based on the definitions provided in the MDS assessment user’s manual (Morris, Murphy, & Nonemaker, 1995, pp. 3.38–3.39).

Basic advance directives included DNRs, durable powers of attorney—health care (documentation regarding who will be legally responsible for health care decisions if the resident becomes unable to make decisions), and living wills (documentation of the resident’s preferences regarding measures used to prolong life when there is a terminal diagnosis). We also included in basic directives legal guardianship, which gives the court-appointed guardian certain responsibilities for health care and other decision making for the resident.

Progressive advance directives included feeding restrictions (decisions to not be fed by artificial means if unable to be nourished by oral means), do-not-hospitalize orders (documentation that the resident is not to be hospitalized, even after developing a condition that usually requires hospitalization), medication restrictions (documentation of the desire to not receive life-sustaining medications such as antibiotics or chemotherapy), and other treatment restrictions (which might include limitations on the use of blood transfusions, tracheotomy, respiratory intubation, etc.). Each of these progressive directives can have a direct and significant impact on the resident’s course of care. Previous investigations have suggested that progressive advance directives rarely occur in nursing homes apart from at least one basic directive (McAuley & Travis, 2003).

We also examined separately the person responsible for decision making for residents. Although not directly related to advance directives for health care, this information offers useful insights into who might be responsible for making the decisions leading to advance directives (Levin et al., 1999; Travis et al., 2002).

Methods

The research utilized national data from MDS assessments that were completed for residents at two points in time: at the point of facility admission and, for residents who had been in a facility for 12 months, at the 12-month post-admission assessment. Admission MDS assessments must be completed by the end of the 14th day after admission. The 12-month MDS assessment must be completed by the end of the 365th day after the most recent full MDS assessment. If a full MDS assessment is completed due to significant change in the resident’s status or condition, then the next 12-month assessment is due one year after this significant-change MDS assessment (Morris et al., 1995). We examined the years 2000–2004. In order to provide the most recent possible information and because full-year 2004 MDS data were not available at submission, we included only those individuals who had completed admission assessments and 12-month assessments by June 30, 2004. However, the number of cases that were available for 2004 should be sufficient to provide a reasonable estimation of advance directives for the full year.

The MDS manual (Morris et al., 1995, pp. 3.38–3.39) provides detailed information regarding how to deal with a resident’s advance directives. The manual also states that “documentation must be in the record for a directive to be considered current and binding.” The manual further defines each specific type of potential directive, as well as the process to be used for determining which directives, if any, are to be included for the resident. States differ regarding the legal status of specific directives, persons completing the MDS are advised to become familiar with relevant state laws and regulations. Although the MDS covers all major types of advance directives, we omitted those that related only to post-death issues (e.g., organ donation, autopsy request).

Our interest was in examining advance directives at admission versus those of residents at their 12-month assessments, rather than performing a direct cohort analysis of directives. Therefore, we did not directly match the 12-month MDS assessments with admissions occurring exactly one year earlier. However, we selected only those 12-month assessments in a given year for which the recorded admission date was in the earlier year (e.g., all 2003 12-month assessments that also had an admission date of 2002 recorded on the 12-month assessment form). Sometimes individuals are discharged and then re-admitted as new residents or have a full MDS assessment due to significant status changes, thus shifting their 12-month assessments (Morris et al., 1995). Therefore, some individuals receiving their
12-month assessments in 2003 would not have been admitted during 2002, and some admissions in 2002 may receive their 12-month assessments in a year other than 2003. Analysis consisted of chi-square tests of 2000 versus 2004 distributions for each type of advance directive for both admission and 12-month assessments, as well as chi-square tests for each directive comparing the distributions at admission in one year with the 12-month distributions in the following year (e.g., 2000 admission living will vs 2001 12-month living will) are significant at the .0001 level and are therefore not listed. Significance levels for each 2000 AD measure versus the same 2004 AD measure (shown in the 2000 vs 2004 column) are: *p < .05; **p < .01; ***p < .001; ****p < .0001.


**Results**

Table 1 displays the admission and 12-month advance directives, as well as the individuals responsible for making decisions. There was a significant increase (40.2% in 2000 compared with 44.8% in 2004) in the percentage of admissions responsible for their...
own decisions and a slight but significant decline across these years in the percentage of admissions who had a family member responsible for decisions. Most admissions had no advance directive, and the percentage who had a directive actually declined a small but significant degree between 2000 (45.3%) and 2004 (44.5%). The percentages of admissions who had each basic directive differed significantly between 2000 and 2004; DNRs and durable power of attorney–health care increased, whereas living wills and legal guardianships decreased. With the exception of other treatment restrictions, which increased very slightly, there were no significant 2000–2004 differences in admission progressive advance directives.

At 12 months, 64.1% to 65.3% of residents had decisions made by family members, with a small but significant decline between 2000 and 2004. More than half of the 12-month assessments had some form of advance directive, and the percentage increased significantly from 59.2% to 62.7%. There was a relatively consistent increase during the 5 years (from 49.9% to 54.9%) in the percentage of 12-month post-admission assessments having a DNR, and the 2004 rate differed significantly from the 2000 rate. Similarly, the percentage of residents who had a durable power of attorney–health care increased significantly between 2000 and 2004. The use of living wills increased very slightly, but significantly, between 2000 and 2004, whereas the percentage of 12-month post-admission individuals who had legal guardians declined significantly during the 5 years (from 7.1% to 6.3%). With regard to progressive advance directives at 12 months, there were significant declines between 2000 and 2004 in the percentage of residents who had feeding restrictions and medication restrictions. The prevalence of residents 12 months post-admission who had do-not-hospitalize orders did not change consistently, but was significantly higher in 2004 than in 2000. There were no significant changes between 2000 and 2004 in the other treatment restrictions directives.

All of the chi-square tests examining differences in the prevalence of each admission directive in one year versus the same directive in the 12-month assessments in the following year were statistically significant at the .0001 level. Individuals who remained in a facility for at least a year were significantly more likely than prior-year admissions to have had decisions made by family members, to have had some form of advance directive, and to have had each of the basic and progressive directives.

Discussion

There are several notable limitations to this analysis. Although the MDS user’s manual (Morris et al., 1995) provides specific definitions for advance directives and requires documentation in the resident’s record, it is unclear how thoroughly or carefully the residents’ records were reviewed in order to identify or update directives. Furthermore, because state laws can influence which directives are legally sanctioned, there may be substantial state variations in trends that we missed in this national analysis. Additionally, there is strong evidence of widely varying interpretations of advance directives by health professionals (Hardin & Yusufaly, 2004; Thompson, Barbour, & Schwartz, 2003) and family members (Ditto et al., 2001), as well as limited consultation of advance directives by critical care professionals (Danis et al., 1991), so the presence of a directive should not be directly associated with adherence with regard to actual clinical care received. Finally, any comparisons of admission assessments and 12-month assessments should take into account the fact that substantial losses occurred during this time period due to live discharges to the community, discharges followed by re-admissions that would delay the 12-month assessment, or death. Future researchers should directly investigate the degree to which differences across time in advance directives among nursing home residents are influenced by these factors, versus changes in end-of-life decision making.

The results demonstrate that between 2000 and 2004, there were significant increases in the percentage of nursing home admissions responsible for making their own decisions, and significant declines in those who had a family member responsible, who had legal guardians, or who had any advance directive. However, it should be noted that these changes are limited from a substantive perspective, with the exception of the large increase in the percentage of residents who were responsible for making their own decisions at admission. The increase in admissions responsible for making their own decisions and the relatively trivial decline in advance directives at admission are among the major findings of this report. Additional research is needed to determine whether the shift toward greater resident decision making, as well as the narrow declines in advance directives at admission, are the result of patient characteristics (such as an increasing prevalence of admissions who are recuperating from acute health problems not associated with terminal decline) or other factors (such as greater attention to assessing the decisional capacity of a resident to execute an advance directive [Allen et al., 2003; Mezey, Misty, Rappaport, & Ramsey, 1997; Mezey, Teresi, Ramsey, Misty, & Bobrowitz, 2000] or presence or type of late-life long-term care at admission [McAuley & Travis, 2003]).

The percentage of nursing home residents who had any advance directive at 12 months in 2004 (62.7%) was significantly higher than that same percentage in 2000 (59.5%), but differed very little from that (59.7%) found in 1996 in a nationally representative sample of current nursing home residents (McAuley & Travis, 2003), even though the MDS includes a greater variety of advance directives than McAuley and Travis were able to assess. This finding suggests that the substantial early gains in the percentage of longer-term residents with directives that occurred just after the promulgation of the PSDA may not have continued into recent years. If there are to be increases in the use of advance directives at admission and at later points in nursing home stays, staff and the health and social services professionals who have opportunities to meet with persons being admitted and after admission may need to be both more cognizant of individuals’ late-life long-term care progression.
as well as more proactive regarding the provision of information, taking into account the importance of personal experiences in making end-of-life decisions (Lambert et al., 2005). Furthermore, strategic information campaigns targeted to the general public and within facilities may be beneficial (Molloy et al., 2000).

Residents at 12 months after admission were substantially more likely than those at admission to have had an advance directive. For some directives, the relative increase in prevalence was quite large. We speculate that the prevalence of directives at 12 months post-admission versus admission was due to the interplay of several factors that could differentially affect the prevalence of advance directives. For example, many people admitted to nursing homes will die before their 12-month assessments. Because prognosis is associated with decisions among elderly adults about using advance directives (Murphy et al., 1994), these individuals may be more likely to have a directive at admission, and their deaths could result in a reduction in the prevalence at 12 months. Similarly, other admissions who recover and are discharged to the community prior to their 12-month assessment may be less likely to have a directive at admission, and their discharges could result in an overall higher prevalence of directives at 12 months. Many individuals who remain in the facility for 12 months may experience declines in health or function and may have hospital stays that could provide another opportunity to reconsider their health care planning. It is also possible that facility staff may have more time to provide health care planning information, and residents and family members may have more time to become adjusted to the fact that the resident will not be returning to the community, resulting in new or extended discussions and decision making about advance directives.

It has been well documented that these decisions are difficult to make. Having time to develop comfort and trust with the resident’s physician and the nursing home staff, and having more time to consider all late-life long-term care options are likely to be enhancements for advance-directive decision making (Travis, Loving, McClanahan, & Bernard, 2001). Clearly, there is a need for more research into the characteristics of people with and without various types of advance directives at admission to nursing homes, as well as the dynamics of change in use of directives over time. Such analyses would be very beneficial in furthering researchers understanding of late-life long-term care in nursing homes by making it possible to identify individuals within each late-life long-term care category, to describe their characteristics at admission, and to understand the changes they undergo within long-term care facilities.

References


Stata Corporation. (2003). Stata statistical software (version 8.0). College Station, TX: Author.


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