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Advance Directives at End-of-Life: Nursing Home Resident Preferences for Artificial Nutrition

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Running Head: ADVANCE DIRECTIVES

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Introduction

More than 67% of Americans died in institutions in 2000, almost half of them in nursing homes [1]. During the past 25 years, many high profile legal cases centered on use of feeding tubes in nursing home residents, including the recent controversy over the life of Terri Schiavo. In this article we examine preferences for artificial nutrition, as stated in the advance directives of nursing home residents, and whether those preferences were honored in the last two months of life. A historical perspective on tube feeding practice, efficacy, regulatory issues and advance directives in nursing homes at end of life provides a basis for discussion.

Historical Perspective

According to reports from the National Hospital Discharge Survey [2, 3], the placement of gastrostomy tubes in older Americans (65yrs of age and older) increased from 61,000 procedures in 1988 to 136,000 in 1997. Although feeding tubes may be used to ameliorate the effects of temporary physical conditions that interfere with ability to eat, they may also be used at end-of-life because of an idiopathic loss of appetite and decreased oral intake. Many clinical situations warrant the use of feeding tubes for treatment of temporary conditions. At the end of life, however, widespread use of feeding tubes is of questionable clinical value and can create ethical dilemmas for patients, families, and clinicians.

Among 1.4 million nursing home residents, 34% require some support to eat [4]. Staffing shortages may unfortunately contribute to feeding tubes [5]. Currently, between

2 and 34% of residents residing in Medicare or Medicaid certified U.S. nursing homes have feeding tubes [6]. In a subset of this group, those with severe cognitive impairment, feeding tubes are used more frequently than for those who are cognitively intact or exhibit only mild impairment [6, 7]. Thus, much of the literature on feeding tubes in nursing homes focuses on residents with severe cognitive impairment.

Although the rates of morbidity and mortality from iatrogenic malnutrition are increased in seriously ill patients [8], no evidence supports the use of feeding tubes to prevent aspiration pneumonia or to prevent or treat pressure ulcers [9-11], nor is there support for the use of feeding tubes for comfort or survival [11].

Regulatory Issues

Nursing home regulations put into place as a result of prominent cases of abuse and neglect in the 1960's and 1970's, require that delivery of food and fluids be sufficient to maintain a minimum average weight unless a specific clinical condition precludes such a treatment goal [12]. These regulations are enforced through a survey process for state Medicaid Programs; violations are reported to the state Office of the Ombudsman. [13].

Weight loss is a key indicator utilized in these surveys, but in isolation is a poor index of quality, and furthermore, is an inaccurate proxy for health status. Variations in equipment, procedures, and staff practices exist regarding data collection on weight, not to mention the arbitrariness of weight due to alterations in muscle mass, fat, or extra-cellular fluid changes. In some instances, weight loss may suggest improper care, but it may also result from decreased appetite, an expected characteristic of many terminal conditions. Despite frequent inevitability of weight loss in many circumstances, fear of liability for potential abuse or neglect may trigger the placement of a feeding tube when

weight loss occurs [10, 13, 14]. Although feeding tubes are more costly than oral nutrition, federal reimbursement obviates these differences by making their use fiscally advantageous [10, 13-15].

In addition to OBRA-87, the Older Americans Act (OAA) [16] provides additional protection regarding nutrition and hydration. Unlike OBRA ’87, OAA does not require resident acceptance of nutrition, adding to further inconsistency regarding to nutritional guidelines and placement of feeding tubes for nursing home residents at the end-of-life [13].

Advance Directives

Prior to 1990, research on advance care planning was limited and focused mostly on do not resuscitate orders (DNR) [17]. The Patient Self Determination Act (PSDA) of 1991 mandated that all residents of long term care facilities be offered information about the right to complete an advance care directive [18]. Similarly, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) developed standards requiring staff in long term care to ask patients about an advance directive (AD) upon admission, and subsequently to offer the opportunity to execute such a directive [19].

Although early reports showed relatively low percentages of ADs and only modest increases in the number of ADs executed since the PSDA [17, 20], recent findings suggest that ADs are more prevalent in nursing homes than in hospitals or in patient homes without hospice services [1]. Demonstration of the effectiveness of ADs, however, is arguable [21]. Two issues are key in this discussion; the best type of advance directive (a living will or a durable power of attorney for healthcare), and the presence or absence of advance care planning as part of the advance directive execution [21, 22].

Although some report a high rate of consistency in care (75%) with a previously executed AD, the presence of the document in the healthcare record at the time of treatment in the nursing home or upon re-hospitalization did not guarantee adherence to resident preferences [23].

Despite literature concerning feeding tube preferences of nursing home residents [7, 24-27], there is limited detail concerning the incidence or frequency with which tube feeding preferences appeared in advance directives. To this end, the purpose of this study was to determine if preferences for artificial nutrition, as stated in the advance directives of nursing home residents, were honored in the last two months of life.

Methods

This study was a secondary analysis of data from the Palliative Care in Nursing Homes Project funded by the Robert Wood Johnson Foundation [28]. These homes were part of Genesis ElderCare, a large geriatric health care company. Most residents had significant physical and cognitive impairments. An average of three to five deaths occurred per home per month. The homes received most of their revenue from Medicare (55%) and Medicaid (15.5%), augmented by other private insurance and private pay [28].

The sample for this study consisted of 57 consented residents from the parent study who died during the study period (April 1999 through April 2001) in six Maryland Community (3 suburban and 3 rural) nursing homes. Residents ranged in age from 62-98 years of age. Most were female (68%), White (90%), widowed (72%), and some were educated at the secondary level or beyond (46% completed 9^{th} grade or more) (see Table 1).

All documentation related to advance directives, changes in weight, and palliative care in the last two months of life was examined. Data were retrieved from advance directives developed by Genesis and required for use in nursing homes. These included *A Directive for Care Directly Given by a Patient* (*Patient executed AD*) and *Instructions for Care Given on Behalf of Another Individual* (*Other executed AD*). It is unclear whether all of the directives that were intended to express patient wishes were in fact completed by patients. Similarly, directives that were to be completed by another individual may in some cases have been the direct wishes of a patient. For this reason, no comparison was made between patient wishes and other individual wishes in this paper.

Weight data were located on three forms developed by investigators for the parent project (see Table 2). *The Palliative Care Worksheet* was completed only for those residents who died during the study period.

Results

Advance Directives

Most residents (87.7%) either completed an advance directive or had another individual complete one on their behalf. Combined results of *Patient and Other executed ADs* in this sample revealed that a striking majority of residents refused (86%) rather than accepted (8%) feeding tubes (see Table 3).

Last Month of Life

Utilization of feeding tubes during the last month of life was retrieved from *The Palliative Care Worksheet* for all residents (57). Four (7.1%) had a feeding tube in the last two months of life, despite expressed wishes in the advance directive; 1 (1.8%) had a feeding tube consistent with the advance directive. Only one resident had a feeding tube

in place at the time the advance directive was executed. Forty three patients (75.4%) did not have feeding tubes, consistent with their advance directives. Three residents had advance directives with no specific information regarding preference feeding tubes and seven residents had no advance directive. These ten residents were classified as receiving care consistent with their wishes. No residents indicating a preference for a feeding tube were denied this option.

Gender was also considered with regard to wishes expressed in the advance directive and placement of a feeding tube. Among 39 females, there were four cases (10.4%) where the advance directive was not followed with regard to tube feeding. Among 18 males, the advance directive concerning placement of a feeding tube was honored. Although these gender differences were not statistically significant (Fisher's Exact test two-sided p=.30), gender difference may have nevertheless been missed (i.e., a Type II error was made). If so, then it is possible that our results underestimate the true percentage of residents receiving care consistent with their wishes, since males were over-represented among residents in the sub-sample. Finally, it should be noted that among the 35 female residents receiving care consistent with their wishes, 1 received a feeding tube and 34 did not. When men and women were compared based on a three-level outcome of preferences (wished followed – received tube feeding; wished followed – no tube feeding; wishes not followed – received no tube feeding), no change in interpretation resulted (Generalized Fisher's exact test p=.38).

Documented Weight Loss and Tube Feedings in the Last Month of Life

As previously noted, four residents had PEG tubes in the last month of life and one had a nasogastric feeding tube. No resident in this group experienced weight loss as

recorded on the *Palliative Care Worksheet* (yes/no). The difference in weights from two months prior to death and at the time of death was calculated to verify the lack of weight loss. Calculations revealed weight loss in one out of five residents with a feeding tube in the last month of life. Overall, weight data were incomplete or missing for most residents in the sub-sample (70%, N=40) making it difficult to interpret documented weight loss.

According to information from *The Identification of a Palliative Care Customer Form*, weight loss occurred in 26% of the residents in the total sample (n=15). Only one of these residents had a feeding tube in the last month of life, and according to data from the *Palliative Care Worksheet*, that resident had no documented weight loss, nor recorded weights for two months prior to death or at time of death.

Finally, weights were recorded for 75% of residents on the *Symptom Tracking Form*. Weights were variable and many trended downward several months before death, with a precipitous decline as death approached. Thus, weight changes were not easily captured, but fit the profile noted in the literature of decline in the last months and weeks of life.

Discussion

Most of the nursing home residents in this sample refused feeding tubes, and these preferences were honored during the last two months of life (93%), despite a small number of residents with documented weight loss (17-26%). A small number (5, 8.8%) of residents did receive tube feedings at end-of-life; of those five, only one was consistent with the advance directive. In a recent report on the use of feeding tubes with nursing home residents [6], the range was 2-34% overall.

Weight loss did not appear as a significant trigger for artificial nutrition in these nursing homes. Perhaps this was due in part to staff awareness of the normal process of weight loss in the dying individual, comfort in caring for the dying, and institutional values [29]. These institutional values may have been based on significant knowledge and comfort with federal and state regulations concerning the provision of adequate nutrition, leading to an acceptance of residents' preferences, without fear of liability. These homes were also undergoing an intervention to improve palliative care, which did in fact demonstrate greater dialogue about and ongoing review of advance directives [28].

In isolation, weight is an insufficient benchmark for assessing in the older adult with dementia, where weight loss is common [30]. Downward declines can be attributed to variability in the scales used to obtain weight, the potential for inconsistency in staff procedures for weighing patients, and the lack of distinction in changes in weight from loss of muscle mass or fat or shifts in extra-cellular fluid. Other reasons for loss of weight include decreased intake secondary to chemosensory changes, gastroparesis, hormonal shifts, and alterations in the central feeding drive [31]. Unfortunately, the problem of weight loss in nursing homes is often viewed as a unidimensional phenomenon (specifically, lack of attention to adequate intake) rather than holistically and comprehensively.

As in many nursing homes, consistencies in documentation remain problematic, and this was the case in these participating homes. We found that several types of documents were used to record information about advance directives and resident preferences, and these were not always congruent with one another, making treatment decisions more difficult for staff.

Conclusion

Despite reports of the ineffectiveness of advance directives [21], and ethical dilemmas concerning withdrawal of feeding tubes, advance directives nevertheless do play an important role with regard to end-of-life decisions concerning artificial nutrition. In this study of six Maryland community nursing homes, residents were three times more likely to have an advance directive (87.7%), as compared to use of formal advance directives in all nursing home residents in 2000 for the State of Maryland (29.3%) [32]. To some extent, the significant use of advance directives by nursing home residents in this study may be attributable to the intervention of the parent study [28].

The overuse of feeding tubes has been reported nationally [2, 3, 6, 33] and locally [32]. The percentage of patients using feeding tubes in this study was only 8.8%, at the low end of national statistics and one third of local usage in 2000 from Maryland State nursing home residents with severe cognitive impairment (25.5%) [32]. Although the level of cognitive impairment for nursing home residents in this study were not obtained, most had significant physical and cognitive impairments.

In this group of nursing homes with an established palliative care program, overuse of feeding tubes was not evident at the end-of-life. We believe this success in these homes is at least partially attributable to advance care planning involving early and ongoing discussion and documentation with residents, families, surrogates, and health care providers, along with corporate policies and support [28]. Moreover, the quality of palliative care training, including a thorough understanding by staff of basic principles of end-of-life care, in conjunction with administrative support, is essential to quality of care for nursing home residents at end-of-life. Future research should examine feeding

practices and prevalence of feeding tubes in nursing homes more broadly, as well as at end-of-life.

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Table 1: Demographic Data

Characteristic	Sample (%)
Age (yrs)	
Unknown	1 (1.8)
<60	0 (0)
60-69	4 (7)
70-79	7 (12.3)
80-89	24 (42.1)
≥90	21 (36.8)
Gender	
Male	18 (31.6)
Female	39 (68.4)
Marital Status	
Divorced/single	4 (7)
Never married	1 (1.8)
Married	9 (15.8)
Widowed	41 (71.9)
Unknown	2 (3.5)
Education	
Unknown	14 (24.6)
≤ 8th grade	17 (29.8)
9-12th grades	18 (31.6)
≥13th grade	8 (14)
Race	
Unknown	3 (5)

African American	3 (5)
White	51 (90)
American Indian	0 (0)

Table 2: Weight Data

Forms	Type of documentation
Palliative Care Worksheet	Yes/No & 2 months prior to death
Identification of a Palliative Care Customer	Yes/No
Physical/Emotional Symptom Tracking Form	Date & weight

Table 3: Execution of Advance Directive feeding preferences

Characteristic	Sample (%)
Without Advance Directive	7 (12.3)
With Advance Directive	50 (87.7)
Patient Executed Advance Directive	
No instructions*	38 (76)
Refused Feeding Tube	11 (22)
Accepted Feeding Tube	1 (2)
Other Executed Advance Directive	
No instructions*	15 (30)
Refused Feeding Tube	32 (64)
Accepted Feeding Tube	3 (6)
Combined Results	
No instructions*	3 (6)
Refused Feeding Tube	43 (86)
Accepted Feeding Tube	4 (8)
Conflicting wishes**	0 (0)

*No instructions = n/a, blank, illegible or instructions unrelated to feeding tube

**Conflicting wishes = resident had 2 directives, one saying yes and one saying no to feeding tube