
Analysis of Advance Directive Documentation to Support Palliative Care Activities in Nursing Homes

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As part of an intervention to improve health care in nursing homes with the goal of reducing potentially avoidable hospital admissions, 1,877 resident records were reviewed for advance directive (AD) documentation. At the initial phases of the intervention, 50 percent of the records contained an AD. Of the ADs in the resident records, 55 percent designated a durable power of attorney for health care, most often a child (62 percent), other relative (14 percent), or spouse (13 percent). Financial power of attorney documents were sometimes found within the AD, even though these documents focused on financial decision making rather than health care decision making. Code status was the most prevalent health preference documented in the record at 97 percent of the records reviewed. The intervention used these initial findings and the philosophical framework of respect for autonomy to develop education programs and services on advance care planning. The role of the social worker within an interdisciplinary team is discussed.

KEY WORDS: *advance directives; code status; durable power of attorney for health care; nursing homes; respect for autonomy*

An increasing number of studies indicate that medical care at the end of life (EoL) can be intense and aggressive. However, this type of approach does not produce good outcomes and may conflict with patient preferences (Ersek & Carpenter, 2013; Obermeyer et al., 2014). The Institute of Medicine (2014) identified that a number of interventions used in EoL care (EoLC) are unlikely to help patients and may be of marginal benefit. In 2009 Medicare spent \$55 billion in hospital and physician costs during the last two months of life. Unfortunately, 20 percent to 30 percent of these expenditures had no meaningful impact, and there is evidence to suggest that some led to increased suffering for individuals (Wakefield, 2012; Walsh et al., 2010).

In addition, nursing home costs average between \$114 and \$136 billion annually, and the costs are highest in the last months of life (Ersek & Carpenter, 2013; Kaye, Harrington, & LaPlante, 2010; Walsh et al., 2010). In nursing home settings, there is also a tendency to use aggressive care at EoL, whether it is in a person's best interest and whether health care providers know a resident's wish for EoLC. This type of care can result in unnecessary and

difficult transitions at EoL (Ersek & Carpenter, 2013). However, some evidence suggests that advance directives (ADs) improve the dying experience for residents and decrease the cost of EoLC through honoring residents' expressed wishes about health care preferences (Garrido, Balboni, Maciejewski, Bao, & Prigerson, 2015; Morhaim & Pollack, 2013).

ADs—HISTORY

ADs, or advance health care directives, were created as a practical means to ensure patient autonomy at EoL (Galambos, 1998; U.S. Department of Health and Human Services [HHS], 2015). They began as simple requests to avoid medical treatment and care that would prolong life in situations in which a patient is in a severe and terminal condition. In the 1960s, largely out of the work of the consumer rights movement and hospice advocates, the earliest type of directive, the living will, was developed. The living will was a simple document that, when enacted, would offer the patient perspective in medical decision making and provided a venue for individuals to voice their wishes for medical care at EoL (Galambos, 1989; HHS, 2015). California

passed the [Natural Death Act in 1976](#), becoming the first state to pass a law on living wills. Soon after, other states passed similar legislation. Federal law did not appear until 1990, when the U.S. Congress passed the [Patient Self-Determination Act \(Galambos, 1998; HHS, 2015\)](#). When the act became effective in December 1991, it affirmed a patient's right to facilitate his or her own health care, to accept or refuse medical treatment, and to make an advance health care directive. The passing of this legislation affected health care institutions that receive Medicare or Medicaid funding because they were now obligated to inform patients, on admission, of their legal rights to enact an AD; to document patients' ADs in the medical record; and to ensure compliance with state laws relevant to ADs ([Galambos, 1998; Kossman, 2014](#)).

ADs help to manage decision making during medical crises and EoLC. They allow individuals to plan for personalized care and can reduce EoL health care costs ([Lubell, 2010](#)). ADs evolved over the years and are increasingly detailed and specific, with options for patients to list their preferences for care. If used properly, ADs can specify patient preferences in several areas of EoLC when people are deemed incompetent and unable to make decisions for themselves. These forms can help users define the amount and kind of care desired when in a terminal state ([Morhaim & Pollack, 2013](#)). An additional component of an AD is a durable power of attorney section, which allows individuals to designate a health care agent to make health decisions for them. These substitute decision makers are also referred to as agents, power of attorney for health care, attorney in fact, or health care representative ([HHS, 2015](#)).

Another type of directive is the do-not-resuscitate order (DNR). The first hospital policies on DNRs were published in the medical literature in 1976 ([Burns, Edwards, Johnson, Cassem, & Truog, 2003](#)). DNRs are intended to allow patients to designate that they wish to forgo cardiopulmonary resuscitation (CPR) in the event of cardiopulmonary arrest. Those wishing to have CPR performed are often referred to as full code. Whether a person designates a DNR or full code is often referred to as a code status. These orders are not intended to apply to any treatment other than CPR ([Beach & Morrison, 2002](#)). However, DNR orders may be a part of an AD and individuals may wish to forgo other life-sustaining interventions as well.

A review of the literature between 2008 and 2013 revealed that 55 percent to 65 percent of U.S. adults greater than 65 years of age living in the community and in nursing homes have ADs. Those with ADs are less likely to receive feeding tubes, to experience transitions between nursing facilities (NFs) and hospitals, and to die in the hospital. There is evidence that AD completion rates increase when health care providers ask culturally sensitive questions and educate patients about ADs ([Kossman, 2014](#)).

PHILOSOPHICAL FRAMEWORK AND ETHICAL CONSIDERATION

ADs are intended to provide patient autonomy and a mechanism for individual choice in EoLC, and as such support patient-centered care. The values of patient autonomy and individual choice fall under the moral principle of respect for autonomy. To respect autonomy is to recognize a person's capacity and perspective, which includes the right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs ([Beauchamp & Walters, 1989](#)).

Most professional codes of ethics support this principle by including language about respecting the inherent worth and dignity of people. The National Association of Social Workers (NASW) *Code of Ethics* has such language and directs social workers to honor a person's right to self-determination ([NASW, 2015](#)). The AD provides a mechanism in which patient autonomy is exercised, particularly for people who are unable to make their own decisions.

THE MISSOURI QUALITY INITIATIVE PROJECT

In 2012, HHS, through the Centers for Medicare and Medicaid Services (CMS), provided funding opportunities for organizations to test original evidence-based clinical interventions to improve health care in nursing homes with the goal of reducing potentially avoidable hospital admissions ([CMS, 2015](#)). The Missouri Quality Initiative (MOQI) is one of seven in the country selected to test a clinical intervention under these guidelines.

MOQI identified 16 skilled-nursing facilities (SNFs) in the Greater St. Louis area to partner with the Sinclair School of Nursing to develop a clinical intervention model. Key components of the MOQI intervention include an advanced practice registered nurse (APRN) in each facility, who guides the intervention, delivering advanced practice care to the

residents and training facility staff to improve their skills. An MOQI intervention team assists with medical care, care transitions, health information technology, and evidence-based INTERACT II assessment tools. The project promotes the use of Interventions to Reduce Acute Care Transfers (INTERACT), which is a set of evidence-based clinical practice tools and strategies developed with funding from CMS to reduce hospitalizations from nursing homes. The tools and strategies assist nursing home staff in early identification, assessment, communication, and documentation about changes of condition in nursing home residents (Rantz et al., 2014, 2015).

The APRN works collaboratively with facility staff on assessment and management of chronic and acute conditions, early illness recognition, and the use of INTERACT II tools; to enhance goals of care and EoL discussions and AD decision making; and to increase the use of health information technology for improved communication. The care transitions component is led by a PhD-prepared licensed clinical social worker, and a licensed MSW serves as the care transitions coach (CTC) (Rantz et al., 2014, 2015).

One of the responsibilities of this care transitions team was to oversee the palliative care goals of the MOQI team with a focus on increasing AD enactment for interested residents. Specific CTC duties are as follows: (a) oversee development of AD educational programs for staff, residents, and families; (b) work with NF staff members and APRNs to improve the AD discussion process with residents and families; and (c) assist staff and administration in developing AD policies and procedures resulting in quality improvement. An interdisciplinary approach is used in education, training, and discussions about ADs and involves the medical director, APRNs, and facility staff to advance the palliative care goals of the project (Rantz et al., 2014, 2015). The literature supports the need for improved interdisciplinary education in nursing homes, particularly in the areas of palliative care and EoLC (Liao & Ackerman, 2008). Our model supports these recommendations. Palliative care activities in the initiative include (a) increasing discussions about EoLC in the facilities; (b) educating NF staff, residents, and families about ADs and EoLC; (c) improving communication in care transitions to ensure that ADs and EoL wishes are known to sending and receiving facilities; (d)

moving toward normalizing discussions about AD and resident care choices within NF operations; and (e) contributing to public dialogue and understanding about ADs and advance care planning.

An interdisciplinary group of stakeholders was formed as an extension of the MOQI team to oversee these palliative care activities. Measuring the impact of the interventions over the course of four years was critical. The purpose of this study was to obtain baseline information about ADs in each of the 16 SNFs. This information allows the research team to focus on specific problem areas and formulate a plan to support palliative care activities.

Study Design and Method

This study was a secondary data analysis, descriptive in nature, of the charts of a cohort of residents living in SNFs who were enrolled in Medicare or Medicaid and had agreed to participate in the study. The analysis was specific to ADs and code status documentation found in the medical records of the MOQI enrollees. The purpose was to establish a baseline data set so that the effect of MOQI palliative care interventions on documented records could be evaluated as the project progressed.

A content analysis of 1,877 medical records of all enrolled residents in each of the 16 facilities was conducted within six months of facility project start-up with the intervention. All records were reviewed for the presence of AD documents. AD documents reviewed included living wills, durable medical powers of attorney, and any other notarized documents referring to EoL wishes. More specific requests such as DNR forms signed by the resident or family members were also examined and documented in terms of code status but are not included in the statistics specific to the AD documents.

These data were collected by an APRN researcher under the guidance of a senior faculty member. The APRN visited each of the facilities enrolled in the MOQI study, reviewing charts and entering data into an Excel spreadsheet developed by content experts. Data were uploaded into SAS and analyzed. The analysis included an examination of the frequency of identified health care choices, completeness and accuracy of existing ADs, and number and type of appointed agents.

Sample

The MOQI sample included 1,877 resident records of Medicare/Medicaid enrollees in the 16 selected nursing homes in the St. Louis, Missouri, area. Prior to enrollee participation in the study, each potential enrollee was informed of the study and provided an opportunity to opt out of the study. The records of residents who elected to opt out of the intervention were not included in this study. Demographic information for residents in the 16 participating facilities is presented in Table 1. These demographics were compared with the resident demographics of the 346 other SNFs in the St. Louis area taken from CMS Minimum Data Set statistics. In the participating facilities, there were higher percentages of female, married residents who were slightly older and slightly more diverse than the comparison sample group.

RESULTS

AD Documentation

AD documents such as living wills and durable powers of attorney were found in 50 percent of the medical records reviewed. These documents allowed for specific health care decisions to be made, such as initiation of tube feeding, intubation, IV hydration, and code status. A summary of the care choices that were designated in these documents is presented in Table 2. Along with AD documentation, separate code status forms were found in 82 percent of the reviewed charts.

In terms of designation of care preferences, the combination of no enteral feeding/do not hydrate/do not intubate (DNI)/DNR was found in 36 percent

of the documents reviewed. DNR alone was designated in 18 percent of documents, and 11 percent contained the combination of no enteral feeding/DNI/DNR. There were several other combinations of health care choices identified, though the majority designated these three choices. In addition to the AD documentation, 97 percent of the resident records reviewed contained a physician order regarding code status, though not all of them had been updated within the past year. This 97 percent figure represents all enrollees in the program—those with ADs and those with a physician order about code status only. This finding is not surprising because state regulations require documentation of code status in resident records.

Designated Agents

All ADs reviewed allowed for designation of a health care agent most often referred to as durable power of attorney for health care (DPAHC). The relationships of the appointed agents to the residents in the records with ADs are summarized in Table 3. Surprisingly, only 55 percent of the ADs named a DPAHC and of those, 62 percent designated an adult child, 13 percent named a spouse, and 14 percent designated a relative other than a child or spouse. The finding that only slightly

Table 1: Resident Demographics for Nursing Facilities in St. Louis Area

Resident Demographic	% Study Facilities	% Comparison Facilities
Female	66	64
Male	34	36
Married	31	27
Widowed	45	44
Never married	11	14
Divorced/separated	13	15
White	88	89
Black	11	10
Other race/ethnicity	< 1	< 1
	M Study Facilities	M Comparison Facilities
Age (years)	79	77

Table 2: Specific Health Care Preferences Identified in AD Documents

AD Health Care Preferences	n	%
Signed DNR	350	26
No enteral feeding/DNR/DNH/DNI	337	25
Signed full treatment (full code)	209	15
Medical power of attorney	204	15
No enteral feeding/DNR/DNI	103	8
Signed DNR/DNH/DNI	47	3
No enteral feeding/DNH	40	3

Notes: AD = advance directive, DNR = do not resuscitate, DNH = do not hydrate, DNI = do not intubate.

Table 3: Designated Agents in Advance Directive Documents

Appointed Agent	n	%
Child	639	62
Friend	19	2
Guardian	9	<1
Other relative	146	14
Spouse	133	13
Unknown	82	8

more than half of the AD documents designated a DPAHC reinforces the need for continued education and training on the advantages and disadvantages of designating a DPAHC. The use of an advance care planning approach that emphasizes health goals and care plans based on a person's preferences and beliefs and elicits participation from significant others in the process may assist in promoting an understanding of the role of a DPAHC. Ideally, the significant others who participate in such an advance care planning process will have increased knowledge about their loved one's preferences and be in a stronger position to participate in critical decisions in the future.

Financial power of attorney (FPA) was sometimes designated in ADs drawn up by the resident's attorney, and this person was almost always the chosen DPAHC. The results were similar for FPA with 61 percent named being an adult child, 13 percent a spouse, and 14 percent another relative. The fact that financial information is coupled with health preferences indicates that there is not a clear understanding that these entities are separate issues. Although one significant other may be the best choice to handle FPA issues and financial matters, that person may not be the best choice to advocate for a loved one's health care preferences. When educating people on ADs, distinctions should be made about the differences in responsibilities between being a financial agent and being a health care agent. Most important, nursing home residents must be comfortable in designating health care agents whom they perceive as having the ability to represent and advocate for their preferences. This point can be more important than birth order or lineage.

DISCUSSION

The prevalence of ADs (living wills and durable powers of attorney) in this study is slightly lower compared with AD prevalence studies of adults residing in assisted-living facilities or nursing homes in the United States. The MOQI study revealed 50 percent compared with 65 percent to 70 percent reported by other authors who completed literature reviews on AD (Jones, Moss, & Harris-Kojetin, 2011; Resnick, Schuur, Heineman, Stone, & Weissman, 2008). In other studies, when DNR, no tube feeding, and no hospitalization orders were included, the rates were as high as 91 percent (Cohen-Mansfield & Lipson, 2008). The highest level of AD completion rates is found among

people receiving hospice care, at 88 percent to 94 percent (Jones et al., 2011; Resnick, Hickman, & Foster, 2012; Resnick et al., 2008). Studies that examined rates of ADs in older adults in the community indicate they are between 55 percent and 60 percent (Hirschman, Abbott, Hanlon, Prvu Bettger, & Naylor, 2012; Ko & Lee, 2010; Matzo, Hijjazi, & Outwater, 2008).

The finding of 50 percent AD completion rate may be due to the fact that the participating facilities are located in Missouri, which traditionally values the preservation of life and is not a state that yet recognizes Physician Orders for Life-Sustaining Treatment (POLST) (Hamed, 2012; Hickman, Sabatino, Moss, & Nester, 2008; Rogne & McCune, 2013). POLST is an approach to EoL planning that emphasizes advance care planning conversations between the patient, their significant others, and health care professionals. These political factors highlight the need for increased education and training on AD's and code status, particularly education and training geared toward nursing home residents and significant others. The CTC in this project provides education and training support to the participating facilities and community at large. The CTC frequently presents at resident and family council meetings and at family and community nights and conducts in-service training for staff. In terms of community outreach, the CTC presents at professional conferences in the community and events for hospital staff and whole departments in hospital settings.

Certain health events are linked to increased rates of AD completion, including diagnoses of cognitive impairment and dementia, surgery, generally declining health status, and recent death of a friend or family member (Levi, Dellasega, Whitehead, & Green, 2010; Lingler et al., 2008). Older adults moving from the community to long-term care facilities are likely to experience health events and generally declining health. This transition period may seem like an opportune time to engage in AD discussions with new residents and family members, but one must also take into consideration that stress levels are high during times of transition. Ideally, these conversations should occur before health crises and transitions, when there is less anxiety and more time for in-depth exploration of issues, fears, and beliefs. Counseling on health care preferences is an appropriate role for social workers who practice as a member of an interdisciplinary team in health care settings. The MOQI model emphasizes an

APRN–social worker team approach in working with residents and significant others on EoL discussions.

There was much variation in the health care decisions identified in this analysis, and to our knowledge these data have not been reported in the literature. Of interest is that 6 percent of the records containing ADs were designated full code compared with 17 percent of the records that had code–status–only documentation. This finding suggests that specific treatment options are more likely to be conveyed if an AD is completed, and the process of completing an AD allows for more in–depth discussion and exploration of treatment options. Residents at SNFs should be given the opportunity to review their designated code status and health preferences on a regular basis and at least annually. Many facilities participating in the MOQI project broach the topic at regularly scheduled resident care plan meetings. In adapting this approach, these discussions are normalized and more likely to occur before there is a medical crisis.

CONCLUSION

The information gleaned from this study provides insight into the decisions on health care choices, appointed agents, and code status preferences made by SNF residents. It contributes to our knowledge about the needs and preferences of this population. Conducting such an audit was useful to the MOQI project in planning education and training events and in supporting caregivers and appointed agents. The chart inventory process can be used at SNFs to assist in the planning and customizing of education events and training for residents, significant others, and staff. Because the inventory revealed that the majority of agents in our sample were adults, children, and spouses, we selected to develop programs geared toward them in each facility. The information obtained from this study can also be used to plan and conduct educational events for agencies and hospitals to advocate for earlier conversations about health care preferences.

Social workers and other health care providers are obligated to respect the autonomy of residents within SNFs. ADs assist with the identification of resident beliefs, desires, and choices and, when used properly, protect residents' self–determination, an important practice value for social workers, physicians, nurses, and other health professionals. In particular, more attention to how ADs and advance

care planning are operationalized in SNFs may help to reduce unnecessary care and burdensome transitions while respecting residents' wishes. ADs help to advance the autonomy of residents who eventually cannot make decisions for themselves and, as such, should be a part of public health policy and health care reform. **HSW**

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