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Abstract

The Center for Medicare and Medicaid Services requires organizations to comply with the Patient Self-Determination Act by having processes that inform patients about their rights to execute an advance directive (AD) and engage in shared decision-making. The aim of this study was to compare AD data from a previous study (1999–2002) to a postenculturation (2011–2015) of a structured process for documented patient's preferences. Second, to conduct a descriptive, bivariate analysis of the enculturated structured ADs process during 2011 and 2015. This *descriptive*, comparative analysis included 500 random patients from four hospitals, and the enculturated descriptive analysis included 302 patients from six hospitals. Comparisons showed less no ADs and a greater institutional ADs post compared with pre ($p < .05$). Fifty-four percent of patients from 2011 to 2015 had an AD, and none of them had resuscitative measures when Do-Not-Resuscitate status was ordered. This enculturated process which includes education for health-care professionals and the community facilitates optimal patient, family-centered care.

Keywords

patient rights, advance directives, living will, resuscitation

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The Center for Medicare and Medicaid Services and The Joint Commission require organizations to comply with the Patient Self-Determination Act (PSDA) of 1990 and have written policies and procedures that inform the admitted patient about their rights to self-determination and executing an advance directive (Koch, 1992). In a 2014 published report from the Institute of Medicine on *Dying in America*, opportunities were offered for improving ways to engage patients and families in advance care planning and shared decision-making. One such opportunity was having electronic storage of patients' documents to improve access and effectiveness of the materials.

In 2002, the Bioethics Department of the authors' organization conducted a study to assess its compliance

with the PSDA. The results showed that only 5.2% of admitted patients had advance directive documents in their medical records and 11.6% of patients claimed to have an advance directive, but never provided the hospital with a copy (Allen & Ventura, 2005). Since that study,

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various initiatives were developed, implemented, and sustained to enculturate a structured process for documenting patient's preferences. Initially, in 2003, institutional advance directive documents (living will, health-care surrogate) were standardized across the then four hospitals and have since remained standardized among all six hospitals within the organization. By 2004, through collaboration with the organization's health information management, a storage system was developed to store admitted patient's advance directive documents that could be retrieved each time the patient was admitted to any hospital within the system. In the subsequent 3 years, as a result of a growing Haitian population, the creation of advance directive documents and education booklet in Creole were developed. These were added to the existing English and Spanish documents. The documents are provided in packets given to each patient on admission.

The Terri Schiavo case in 2005 about a woman in a persistent vegetative state whose end-of-life wishes were not clearly known, caused an emotional nationwide debate over right-to-die and quality of life (Quill, 2005). This sparked community requests from various churches and organizations for the Bioethics Department to conduct education on advance directives. Since then, community education on advance directives continues to be offered regularly to a variety of diverse groups. Recent evaluation feedback from community education attendees noted that at least 40% indicated that they will complete an advance directive and plan to help others complete one as well. By 2012, an advance directive video in English, Spanish, and Creole was created as an additional patient and family education resource available on the patient's education channel. Between 2010 and 2014, this organization moved to electronic documentation and developed structured advance directive questions related to the capacitated and incapacitated patient.

It is the admitting nurse's responsibility to ask advance directive questions of each patient on admission and assist the patient if they wish to complete one. If the admitted patient is incapacitated and a copy of a legal decision-maker is not found stored and validated, a notice is sent to the case manager assigned to that unit, for his or her assistance in finding the right legal decision-maker for the incapacitated patient. This is to ensure that the incapacitated patient rights are respected and honored through a legally identified voice representing the patient, and collaborating with the health-care team in goals of care plans.

The Code of Ethics for Nurses, Provision 1.4 (2015) states that "nurses should promote advance care planning conversations and must be knowledgeable about the benefits and limitations of various advance directives documents" (p. 2). Educating nurses to fulfill this role

at this organization has remained a priority and a goal for the Bioethics Department. Advance directives education is incorporated in the on-boarding orientation for all newly employed nurses and is also coordinated as continuing medical education or continuing education workshop or conferences throughout the year for nurses, case managers, physicians, and other employees. Since various education and documentation initiatives were implemented during 2003 and 2011 to enculturate a structured process for advance directives and honoring patient's preferences within this health system, it was necessary to assess the effectiveness of these initiatives comparing pre- and postenculturation data processes.

Review of Literature

A study was done by Rao, Anderson, Lin, and Laux (2015) to assess U.S. adults who did or did not have an advance directive and factors associated with completing one. From the 7,946 respondents, only 26.3% had an advance directive, and the most frequently reported reason for not having one was lack of awareness (Rao et al., 2015). Ethnic differences in completing advance directives have been studied over the years and continue to show that Blacks are more likely to choose aggressive care and having lower rates of advance directives completion (Zaide et al., 2013). Efforts have also been made to improve advance care planning discussions and completion by various groups such as the national comprehensive cancer center. Zachariah et al. (2017) reported on a 4-year effort on improving advance directives capture rates in specific patient groups—those undergoing surgery, those with metastatic disease, and those undergoing hematologic transplant. They developed disease-specific workflows, created multilingual advance directives workshops, created policies, leveraged electronic medical records, deployed screening questions, and created a culturally sensitive campaign. The advance directives capture rates increased in transplant patients by 65%, bladder cancer patients by 68%, and pre-anesthesia testing clinic by 35% (Zachariah et al., 2017).

While advance directives have been widely used in the United States as a result of the PSDA, other countries over the years have explored the legal status of advance directives. Some have implemented its use based on different values, ethical concerns, and sociopolitical reasons. Horn (2014) discussed the differences between advance directives use in England and France. She stated that since 1985 English law respect for patient autonomy has been a dominant ethical principle that often precedes the doctor's duty to provide optimum medical care to save a life. The Mental Capacity Act of 2007 made advance directives legally binding under English statutes, allowing a capacitated person 18 years and older the autonomy to refuse specific treatments; and such

patient's written advance directives regarding life-sustaining treatments are honored even when incapacitated (Horn, 2014). The French law on advance directives according to Horn was enacted in 2005. The government and physicians were previously reluctant to introduce documents allowing anticipating treatment preferences because such requests were proposed by the euthanasia-lobby. The law therefore specifies both the conditions under which a physician can lawfully discontinue treatment at the end of life and the right of a patient to refuse life-sustaining treatment. However, the physician is not required to accept such a request, is under no obligation to respect an advance directive, and ultimately, it is the physician who decides whether to discontinue a treatment. This supports a very weak position for patient self-determination regarding treatment refusal in France (Horn, 2014).

In Italy, there were heated debates in past years involving political parties and the Roman Catholic Church on the role of advance directives related to the moral and judicial importance of informed consent, permanent incapacity, artificial nutrition or hydration, and withholding or withdrawing treatments (Gristina, Martin, & Ranieri, 2012). However, in a recent article by Ciliberti, Gulino, and Gorini (2018), they discussed a new law approved by Italian Parliament concerning "Rules on informed consent and advance directives" that strengthens the patient's autonomy, eliminating uncertainties on issues such as refusal of life-sustaining treatments. It also supports the need for extensive education of health-care professionals and citizens (Ciliberti et al., 2018). Evans et al. (2012) reported that since 2009, the German Parliament passed a law indicating that providing treatments detailed in a patient's advance directives as unwanted is a physical assault. Their study assessed attitudes, use, and health-care professionals' compliance with advance directives. Results showed that although there was increase awareness of advance directives, there remained low use, poor communication, fear of abuse, and some noncompliance and contradictory evidence regarding bindingness (Evans et al., 2012).

Purpose

The purpose of this research study was to compare advance directives data from a previous study (1999–2002), to postenculturation of structured advance directives processes and sustainability during the period of 2011 to 2015, for four hospitals. Second, to conduct a descriptive and bivariate analysis of the enculturated structured advance directives process for all six hospitals, during the period of 2011 to 2015 to include:

- (a) Description of the relationship with having an advance directive and various socioeconomic factors (insurance type, age, race, and gender).

- (b) Description of the relationship with having an advance directive and reason for hospitalization, outcomes of hospitalization, and sentinel events such as need for resuscitative measures.

Methods

Design

The research design was a descriptive comparative study utilizing accessible data from the previous descriptive study (1999–2002) that included only four hospitals and used as a comparative analysis, using only data from the applicable four hospitals (2011–2015). In addition, retrospective medical record review of randomly selected patients admitted to all six hospitals during the period of 2011 to 2015 was selected for a descriptive and bivariate analysis of the enculturated structured advance directives process. After institutional review board approval was granted, data collection commenced.

Setting

This study was conducted at the six adult care hospitals of a health system with 2,251 beds in the southeastern area of the United States. Four adult acute care hospitals were classified as community hospitals, and the remaining two acute care hospitals were classified as rural hospitals.

Sample

The previous study had a minimum sample size of 250 records distributed. This sample size was determined using a 3% margin of error and an estimation of 30% of inpatients having prewritten advance directives in their medical records (Allen & Ventura, 2005). A similar sampling procedure was chosen for this study to facilitate comparative analysis, totaling 500 de-identified medical records. For the enculturated descriptive analysis, 302 randomly selected medical records from all six hospitals were studied. The number of medical records selected from each hospital was in proportion to the number of patients each hospital contributed to the entire population.

Definitions

The definition of an advance directive is not universal among researchers or even states. For the purposes of this study, advance directives is defined as a document completed by a capacitated patient giving instructions regarding medical care should he or she become incapacitated. These documents are a living will, health-care surrogate, or durable power of attorney for health

care. Excluded from the definition of advance directives were hospital-initiated Do Not Resuscitate (DNR) physician orders, prehospital DNR physician order, and the Proxy Appointment using the Legal Next-of-Kin Hierarchy to identify the legal decision-maker for incapacitated patients without an advance directive. An "Institutional Advance Directive" is a document formatted with the organization's logo on the cover and the content with language similar to the language of the state's advance directives document. It provides an admitted, capacitated patient the opportunity to designate his or her health-care surrogate (primary and alternate, if necessary) and complete a living will if they wish to do so. When "Personal Advance Directives" is mentioned, it is referring to the patient's own legal document (living will, health-care surrogate, or durable power of attorney for health care) that was created outside of the hospital and a copy provided to the hospital and placed in the patient's medical record. It is also noted in the study that some patients "claimed to have an advance directive" and those were patients who stated that they had an advance directive but never provided the hospital with a copy.

Advance Directives Storage Process for Enculturation

The electronic documentation system allows each admitted patient to be asked to review and validate their stored advance directive documents. Patients also have the right to revise their documents as necessary. The revised documents are subsequently stored as the most current documents under the patient's medical record. This process was validated as effective in the poststudy group when the study identified one patient with a stored durable power of attorney document naming two people to make health-care decisions. During the poststudy admission, the patient was asked to review the stored document and proceeded to make changes by completing a new institutional advance directive naming only one of the previous two people to make health-care decisions. In addition, four patients had stored living wills and when admitted during the poststudy period, they completed designation of health-care surrogates on institutional advance directives.

Data Collection and Ethical Considerations

Records were reviewed based on a randomization scheme using computer-generated numbers that would allow all patient records to have an equal opportunity of being selected. The method used was to determine the first admission number given to a patient on January 1, 2011 and the admission number assigned to the last discharge on December 31, 2015. The medical records of

patients that corresponded to those admission numbers were pulled and studied.

The data collection instrument was created by the principal investigator (PI) and was the same instrument used in the previous study of 1999 to 2002. De-identified data collection included age, gender, race, ethnicity, marital status, religious preference, principal language spoken, employment status, number of dependents, insurance type, diagnosis-related group (DRG) for most recent admission, type of admission, number of admissions under this medical record, presence of institutional or noninstitutional advance directive, type of advance directives, occurrence of emergency (code blue) requiring treatment, and compliance with patients' wishes during such events, discharge status, and length of stay in days. A census tract website (U.S. Census American Fact Finder) was used to collect a census tract number based on each patient's address or zip code as recorded in the medical records and obtained at the time of the chart review to avoid collecting the patient's actual address. The purpose of this variable was to estimate income level based on the U.S. Census 2015 data.

Ethical considerations were facilitated throughout this research study to ensure that patients' protected health information was kept confidential. An informed consent was not applicable because this study utilized secondary analysis of existing chart data. Confidentiality remained by using de-identified data, including not identifying the hospitals from which the data were collected. All data from the data collection tool were entered by the PI and co-investigators in an Excel database located in a password-protected database, only accessible by the PI and co-investigators. The data collection tool contained the medical record number as well as the computer-generated randomized number which was listed on the data collection tool as Subject Identification No. The data collection tool was shredded after data were entered in the password-protected database. In addition, once data analysis was completed, the medical record numbers were removed to ensure data were de-identified.

Patients excluded from this study were those admitted as a 23-hour admission or other noninpatient status, patients who reside outside the hospital's service coverage area, those patients under 18 years of age, and if the hospitals were holding patient files under additional security for legal or regulatory reasons or if the patients were still being treated as inpatients at the hospitals. This was consistent with the exclusion criteria of the previous study (Allen & Ventura, 2005).

Data Analysis

The collected data were statistically analyzed using SPSS 19.0 (IBM Corp, 2010). Descriptive statistics

were conducted for pre- and poststudy time periods. Data analysis from the previous study (1999–2002) which included only four hospitals was compared with the postculturation data analysis of 2011 to 2015 for those four hospitals using bivariate comparison of proportions. The p value was set at .05.

Results

Descriptive Analysis of Prestudy and Poststudy, Four Hospitals (n = 500)

The subgroup of the four hospitals for the poststudy group (2011–2015) of 250 participants included an average age of 58 years with 154 (64%) females along with an average median household income of \$53,053. The majority of the sample were White Hispanics (58%, 144) and English speakers (77%, 192). Furthermore, 120 (48%) were married and 240 (96%) had a religious preference. For the comparative prestudy group (1999–2002) of 250 participants, the average age was 55 years with 158 (63%) females along with an average median household income of \$47,030. The majority of the sample were

Hispanics (44%, 110) and English speakers (76%, 193). Furthermore, 148 (59%) were married and 200 (80%) had a religious preference. The average length of stay was reduced by one day in the poststudy group (3.99 days) compared with the prestudy group (4.77 days). Similar to the previous study done in (1999–2002), where the highest percentage of patients who completed an institutional advance directive were assigned a DRG related to childbirth through either vaginal delivery or cesarean section (28%, 70; Allen & Ventura, 2005), the poststudy group identified this same DRG as the highest (25%, 76).

Comparative Analysis of Four Hospitals

The prestudy group had more personal advance directives (13, 5.2%; Allen & Ventura, 2005) compared with the poststudy group (6, 3%), which were all found stored in the medical records. Comparison of pre- and poststudy showed statistically significantly less patients post with no advanced directives (121, 48%) compared with pre (208, 83%; $p < .05$, see Table 1). There was a statistically significant greater number of patients post with institutional advance directives (126, 50%) compared with pre (86, 34%; $p < .05$, see Table 1). Whereas there was a statistically significant greater number of patients with claims to have advance directives pre (29, 12%) compared with post (3, 1%; $p < .05$, see Table 1). In addition, there was no difference in the number of patients having DNR orders, in the prestudy (8, 7.6%) compared with the poststudy (7, 5.6%), and mortality in both groups was the same (4, 3%). None of the patients in either groups had resuscitative measures when DNR status was ordered. Table 2 outlines the comparative analysis of institutional advance directives pre and post.

Table 1. Comparative Analysis of Prestudy Versus Poststudy, Four Hospitals (n = 500).

Variable	Prestudy (n = 250)	Poststudy (n = 250)	
No advance directives	208 (83%)	121 (48%)	$p < .05$
Claims to have an advanced directive	29 (12%)	3 (1%)	$p < .05$
Institutional advance directives	86 (34%)	126 (50%)	$p < .05$

Table 2. Comparative Analysis, Prestudy Versus Poststudy, of Institutional Advance Directives, Four Hospitals (n = 212).

Variable	Prestudy (n = 86)	Poststudy (n = 126)
Age, mean (years)	54.22	56.36
Median household income, mean	\$48,511.33	\$51,514.79
Hispanic, n (%)	53 (50.5%)	66 (52.4%)
Highest admit type, n (%)	Routine elective admission, 56 (53.3%)	Emergency admission or urgent admission, 74 (58.7%)
LOS, mean (days)	4.77	3.99
Mortality, n (%)	4 (3.8%)	4 (3.2%)
Having a DNR order, n (%)	8 (7.6%)	7 (5.6%)
Requiring proxy designation, n (%)	17 (19.8%)	2 (1.6%)
Having resuscitative measures, n (%)	0	0

Note. LOS = length of days; DNR = do not resuscitate.

Descriptive Analysis of the Poststudy (2011–2015) Enculturated Group (*n* = 302)

For the total poststudy group (2011–2015), the average age was 59.1 years with 186 (62%) females along with an average median household income of \$57,021. The majority of the sample were White Hispanics (186, 62%) and English speakers (217, 72%). Furthermore, 142 (47%) were married, and 287 (95%) had a religious preference. While 208 (69%) of patients were admitted as urgent or emergent, the majority of the study group 139 (67%) were discharged home, and the average length of stay was 4.68 days. Mortality accounted for 10 (3%). Table 3 outlines the descriptive analysis of the poststudy in six hospitals.

Advance directives documents found in the medical records of this postenculturated study group represented 163 (54%), with 10 (3%) having stored personal advance

directives and 155 (51%) having an institutional advance directive, as shown in Figure 1. Health-care surrogates represented the highest percentage of documents completed 278 (92%) among this poststudy group, with 15 (5%) having living wills and 9 (3%) having durable power of attorney for health-care documents. Of the 155 (51%) institutional advance directives, 58 (19%) were found stored during the admission period 2011 to 2015 and the remaining 97 (32%) were patients who went on to complete an advance directive once admitted during the period of 2011 to 2015. Table 3 outlines the descriptive analysis for the poststudy (2011–2015) enculturated group.

Of the 141 (46%) of patients with no advance directives during the poststudy (2011–2015), 28 (20%) were documented as incapacitated requiring a proxy appointed legal decision-maker using the legal next of

Table 3. Descriptive Analysis of Postenculturation, Six Hospitals (*n* = 302).

Variable	<i>n</i>	
Age, mean	59.1 years	18–96 years
Females, <i>n</i> (%)	187	62%
Median household income, ^a mean	\$57,021	0 – \$121,434
Racial makeup, <i>n</i> (%)		
White Hispanic	187	62%
White	66	22%
Black or African American	33	11%
Other and NA	18	6%
Language, <i>n</i> (%)		
English	217	72%
Spanish	82	27%
French	3	1%
Married, <i>n</i> (%)	142	47%
With religious preference, <i>n</i> (%)	287	95%
Highest type of admit, <i>n</i> (%)	Emergency or urgent admission, 208	69%
LOS, mean (days)	4.68	1–50 days
Having a DNR order, <i>n</i> (%)	21	7%
Requiring proxy designation, <i>n</i> (%)	25	8%
Having resuscitative measures, <i>n</i> (%)	0	0%
Mortality, <i>n</i> (%)	10	3%
Highest DG for institutional AD, <i>n</i> (%)	OB, 39	25%
Second highest DG for institutional AD, <i>n</i> (%)	Cardiac, 27	17%
Personal AD, <i>n</i> (%)	10	3%
Stored personal AD, <i>n</i> (%)	10	3%
Institutional AD, <i>n</i> (%)	155	51%
Stored institutional AD, <i>n</i> (%)	58	19%
Going on to complete institutional AD, <i>n</i> (%)	97	32%

Note. AD = advance directive; LOS = length of days; DNR = do not resuscitate; NA = not applicable; DG = diagnosis group.

^aBased on U.S. Census 2015 data.

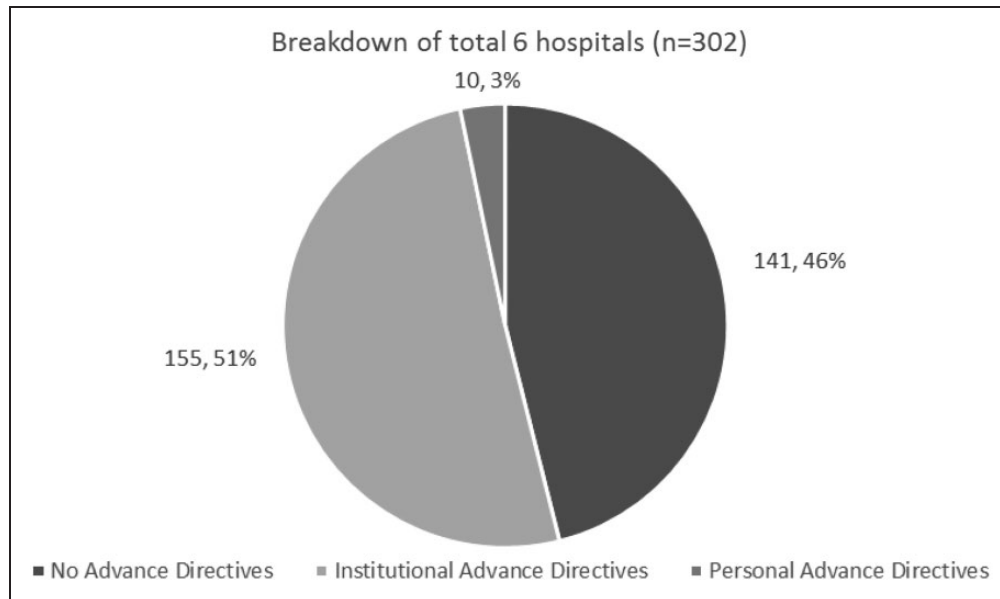


Figure 1. Breakdown of Advance Directives in Poststudy Group.

Note. 306 advance directives are represented due to four patients with both personal and institutional.

kin hierarchy. Of the patients who had DNR status during the poststudy period, 4 (19%) had an out of hospital DNR order and the remaining 17 (81%) were admitted patients whose goals of care preferences were changed to DNR during their hospital stay. The DNR status was honored (21, 100%) for all these patients throughout their hospital stay.

Discussion

The sustained enculturation of a structured process for documenting patients' health-care preferences and honoring those preferences has proven efficient and successful at this organization. Overall, patients admitted in the poststudy subgroup of four hospitals (2011–2015) had advance directives documents found stored as personal (6, 3%) or institutional (126, 50%), compared with only (13, 5.2%) personal and (86, 34%) institutional in the prestudy (1999–2002) group. In a recent study done by Portanova, Ailshire, Perez, Rahman, and Enguidanos (2017), they explored longitudinal trends in advance directives which showed that although Blacks and Hispanics had similar rates of advance directives completion overall (16%), Blacks but not Hispanics had increasing rates of advance directives completion between 1998 and 2012. The increase use in Blacks was felt to be indicative of education programs targeted for Blacks (Portanova et al., 2017). Our study findings proved otherwise, where White Hispanics were the majority of poststudy participants with an advance directive (62%); followed by Whites 22% and Blacks 11%. This supports that ethnic groups even Hispanics can

positively be impacted when education and advance care planning conversations are held. Types of advance directives completed in the United States were assessed by Yadav et al. (2017) and showed that one in three adults completed advance directives with 29% having living wills and 33% power of attorney for health care. In our poststudy group, 92% of patients completed health-care surrogate documents, 5% living wills, and 3% power of attorney for health-care documents.

When the vulnerable incapacitated patient is admitted to a hospital, unless their wishes are found documented or are expressed through someone who communicates on behalf of the patient, it becomes challenging for the health-care team to know whether the care provided is what the patient would have wanted. The electronic process facilitates retrieving and validating incapacitated patients' stored advance directives or timely proxy appointment of a legal representative for those without prior advance directives. This facilitates care decisions that are based either on patient's prior expressed wishes or in the patient's best interest. For this study, 46% of patients had no advance directives of which 20% were incapacitated requiring proxy appointment using the legal next of kin hierarchy. To further ensure that patient's preferences were honored, the study examined whether patients with DNR status received cardiopulmonary resuscitation and found that none of the patients with a DNR order were resuscitated. Yuen, Reid, and Fetters (2011) discussed strategies to improve outcomes with DNR orders that support patient autonomy and prevent nonbeneficial interventions. The overall recommended strategies were to change culture, optimize

communication, promote care that is patient centered, and respect patient preferences at the end of life. The enculturated processes implemented at this organization aimed at achieving those goals as evidenced by the results of this study showing that none of the patients with DNR orders received cardiopulmonary resuscitation. Mortality accounted for 3% of the poststudy group and were patients with DNR orders.

It is evident from this study that providing education and advance directives information prior to a hospital admission can positively be associated with advance directives possession. This was validated when the highest DRG group with advance directives was found to be those assigned to a DRG related to childbirth who received preadmission packets with advance directives. These preadmission packets were sent either to the patient's home or given to them a few days before the hospital admission day, allowing more time to read, discuss with loved ones, and make informed decisions. Knowing this, our ongoing efforts will be focused on community education of the diverse population we serve, and to continue partnering with national initiatives such as "The Conversation Project" in educating health-care professionals and the public on the importance of advance health-care planning (Goodman, 2010). With the enculturation of a structured advance directives process, this study supports its success of providing patient education, allowing patients to formulate new advance directives documents and to retrieve stored documents on admission with the ability to review and revise as needed. This was validated when four patients made updates to their stored documents during the poststudy (2011–2015) admission by designating new health-care surrogates. By electronically documenting patients' goals of care preferences, we can optimize clinician-patient communication, satisfaction, and care delivery outcomes.

Limitations

Limitations of the study included the use of medical chart data which inheritably have high missing and inconsistent data. However, both study periods included random selection of charts, and only completed charts were included. Another limitation was the nonexperimental descriptive comparative design with an intervention. However, the study did not seek to assess efficacy of the enculturation of advance directives but instead focused on comparing the proportion of advance directive.

Implications for Practice

A key factor for subsequent admissions is not having patients redo an advance directive or having to bring

in a copy from home each time. A storage system facilitates a smoother admission process for patients and their families. Having a stored advance directive for the incapacitated patient helps with early identification of the legal decision-maker. This is of great benefit to the health-care team caring for the patient, allowing timely collaboration with the legal decision-maker to provide care based on patient's preferences. Education for nurses, physicians, and all members of the health-care team on the types, benefits, and limitations of various advance directive documents allows them to optimally advocate for the rights of patients and achieve outcome goals.

Conclusion

Health-care professionals can best provide quality, patient, family-centered care when patient's preferences are known through documented advance directives. Having an electronic process for storing the admitted patient's advance directives to facilitate retrieval at future admissions is a great advantage and meets the Institute of Medicine quality standard goals.

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