

Assessing the needs for advance care planning education in county hospital community clinics in Dallas, USA

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ABSTRACT

Currently the number of completed Advance Care Directives are low within the U.S., this number is surprising especially with the Center for Medicare and Medicaid Services (CMS) releasing the final payment rule in 2015 which allows for reimbursement of the discussion on Advance Care Planning (ACP) particularly Advance Directives (AD) of Medicare recipients (Zeitoun, 2015). This number is particularly low amongst persons in lower socioeconomic areas who live near or visit a community health center. Therefore present study was undertaken to examine the need for structured ACP education particularly on Advance Directive within the Dallas county hospital community health centers. With the use of a self-administered questionnaire, patients and caregivers visiting the community health centers were surveyed in the geriatric (persons 65 and older) unit. Persons accompanying the patient to the centers the day of the survey were considered as caregivers. Thematic analysis were used to examine the associations between knowing what advance care planning is, being interested in wanting to learn about advance care planning, having those plans written down, and preference to learning about advance care planning in a group session or privately. Data demonstrated that of the 102 respondents, 73.5% did not know what Advance Care Planning was. The majority of the respondents (80.4%) was interested in learning about Advance Care Planning and preferred it to be in a private setting. These data indicate amongst Dallas County hospital community health center participants, knowing what Advance Care Planning is and having those plans written down is low and highlights the need for structured education about the topic in the county hospital community health centers.

INTRODUCTION

Completion of Advance Care Planning (ACP) is low amongst the U.S. population although ACP is considered to be vital to future care plans especially for those that are in the older adult population (AGS, 2017). One of the most common reasons for the lack of completing the advance care plans specifically advance directives was knowledge of the plans. Amongst the United States older adult population (60 and over) very few have some form of advance care planning in place although they are likely to be suffering from several chronic issues that can cause those plans to come into action. The literature revealed the low number of older adults with advance care plans, reasons why the plans are not made, benefits of having advance care plans, the impact it has if not completed, and where information on advance care plans were obtained.

Autonomy, a principle of ethics, allows a person to be independent and at free will of making choices about themselves. Having autonomy requires decision making that most people prefer even at a young age (Kuczynski, et al. 2018). However as with children an adult can quickly come to realize that making their own choices is not in their hands but of a surrogate, when the person is unable to competently speak and choose for themselves (Howard, 2017). As an adult, wishes can be honored

and even legally documented in the case of not being able to verbally express it, however with the lack of notation, the wishes of someone could possibly be forgotten or even discounted if the surrogate allows their own personal feelings, values, and beliefs to sway decision making (Batteux, Ferguson, and Tunney, 2019).

ACP is the process which allows for a person to make their preferences regarding future medical care be known. The intention of Advance Care Planning is to provide guidance on the medical care of a person that is consistent with their wishes, values, and goals. Planning requires for family, health providers, and patients to communicate while considering the culture and relationship of the patient which will steer decisions regarding medical treatment are made and noted in a document such as an advance directive (NIA, 2018). ACP includes Advance Directives and other documents such as wills.

Types of Advance Directives

Advance Directives are legal documents that provide the step by step instructions of what type of medical care you wish to have. Advance Directives has several parts which include the Living Will and the Durable power of attorney for health care. In addition to the two documents mentioned there are

additional documents that can be added to document your medical wishes (NIA, 2018).

The Living Will is a document that provides instructions to the doctor explaining your wishes should you become terminally ill or permanently unconscious. In the living will, topics such as life support and resuscitation methods are covered. In addition some living wills may include preferences regarding hospitalization, pain control, and the use of life sustaining equipment such as defibrillators and ventilators. This document goes into effect when someone is terminally ill without any chance of recovering.

Durable power of attorney for health care is a document that provides the name of a surrogate, chosen by the patient, who will make their medical decisions when the patient has lost the capacity to. This document assists in the planning for the future in the event of unforeseen situations. This document goes into effect when someone is incapacitated.

Additional documents include:

DNR (do not resuscitate) order provides instruction to medical staff to not resuscitate you if your heart normal rhythm stops.

Non hospital DNR order provides emergency medical staff instructions to restore heartbeat or breathing if you are not in a hospital or other forms of medical facilities.

DNI (do not intubate) order provides instruction to medical staff to not put you on a breathing machine.

Organ and tissue donation is a document that permits your organs or body parts to be donated and transplanted to another individual if a generally healthy person passes away.

POLST (Physician Orders for Life Sustaining Treatment) and MOLST (Medical Orders for Life Sustaining Treatment) forms provides instructions to medical staff when you are critically ill or terminal and know that certain decisions will have to be made to guide your care in the event that there is an emergency.

Who complete Advance Directives

The rate of completion for Advance Directives differs amongst age, economical, racial, support, and religious status. A study on completion of advance directives amongst U.S. Consumers noted

that the completion of directives was associated with higher income, older age, more education, and less frequent in persons that were non- white (Rao, Anderson, Lin, and Laux, 2015).

One in three adults have completed advance directives (Yadav KN, Gabler NB, Cooney E, et al, 2017) with a higher percentage being older, those 65 and older, and with chronic illnesses (Rao, et. al, 2015). Whites are two to three times likely to have advance directives more so than Blacks and Latinos (Carr and Luth, 2017), women more so than men, and older adults within any racial group who have lower levels of income, assets, and education are less likely to complete any form of advance care planning (Carr, 2012). Adults who have a great level of support and tight knit family kinships are likely to complete AD, while those who consider religion as very important are less likely to have AD, citing that their life is in God's hands (Carr and Luth, 2017).

Reasons for non-completion of Advance Directives

Amongst those persons that were non-white, race disparities has been noted as the reason for the incompleteness for advance directives. Carr and Luth (2017) noted that the racial disparities reasons included access to medical and legal personnel to assist with the completion, the ability to read and write, language barriers, religious beliefs, distrusting medical institutions, and believing that family will collectively make the decision on their behalf.

Other noted lack of completions amongst any racial group included deeming it unnecessary (Free, Eubanks, Parker, and Hershey, 2006), the lack of awareness, religion, the lack of understanding what advance directives is, and their family knowing their wishes (Rao, et. al, 2014). A brief by the CDC noted that the lack of awareness, denial, confusion, and cultural differences as the reason for not completing the AD (Benson and Aldrich, 2012).

Barriers in completing Advance Directives

Several studies have noted that there are numerous barriers in patients completing Advance Directives (AD). These studies have revealed that barriers are with patients and physicians for the lack of completion. Patients' most common barrier is knowledge of AD. Other noted barriers for patients include the lack of interest, being isolated socially, believing that choosing family or friend to be a

surrogate will be a burden, the lack of having a trustworthy proxy, understanding health material and having the ability to make decisions, spiritual, cultural, and racial traditions, and waiting on their physicians to begin the discussion (Spoelhof and Elliott, 2012).

Physician related barriers include being uncomfortable with the topic, lack of time to review information with patient and possible surrogate, lack of organization support, waiting on the patient to begin the discussion, and until recently there was no reimbursement (Spoelhof and Elliott, 2012).

Benefits of completion of Advance Directives

The benefits of completing advance directives include decreasing the stress associated with end of life, increase communication between providers and the surrogate, decrease in end of life care cost, and the reduction of confusion and feelings of guilt in family members particularly surrogates can decrease (Wollen and Bakken, 2016). In addition, the respect and wishes for medical care is noted, limitations of unwanted medical treatment is set, there are fewer in hospital deaths, and there is an increase in quality of life and patient satisfaction (Lum, Sudore, and Bekelman, 2015).

Where information on Advance Directives is obtained

There is very little study that has been completed on the most common place people obtain the information on advance directives, however the information is likely gained when visiting a healthcare setting or initiated when a patient is near the end of life (Leod-Dyess et. al, 2014).

A visit to a primary care office could be a useful setting for advance care discussions although many have not utilized it. In addition a survey study of primary care patients on Advance Directives conducted by Sullivan et al (2015) noted that patients prefer the discussion in an outpatient setting. Outpatient settings include locations that provide ambulatory care. Ambulatory care settings can include community health centers, urgent care centers, retail clinics, dental offices, and non-hospital based clinics to name a few (CDC, 2020).

Community based initiatives has been viewed as a route that shows future success in providing and learning about advance care planning which include Advance directives, to a wide range of older adults.

The community initiatives have shown to tailor programs to meet the religious, language, cultural, and social needs of the populations that they serve (Carr and Luth, 2017).

In addition the initiatives have been found to be a source to receive services and goods amongst individuals who are at a disadvantage and have limited access to health care treatment and education, especially amongst the ethnic minority population (Cyril et al, 2015).

When considering Community based initiatives it include community health centers which provide a patient centered approach aimed at providing access and quality of care (Sigounas, 2018). There is limited research on community health centers being an avenue to learn of ACP however with research showing that unless you are of an higher educational and economical status with assets, estate planning and other advance care planning is not considered possibly until you are in a hospital or clinical setting (Rao, et. al, 2014), community health centers could be the connection to ACP for those who are less likely to complete them.

Community Health Centers

Community health centers are patient and community based facilities that serve populations that have limited access to health care (CDC, 2018). From a response to the War on Poverty caused through the civil rights movement, The Office of Economic Opportunity (OEO) originally established the concept of community health centers in the 1960s. OEO called the centers "neighborhood health centers" and they focused on providing access points to health and social services to medically under-served and deprived populations (Taylor, 2004). At that time the centers used extensive community involvement to ensure an inclusive response to the needs of the community.

The concept of community centers and its establishment of the first health center have always aimed at providing preventive and comprehensive care to those who would not otherwise have access to it. Services could range from primary care, dental care, and mental and behavioral health services depending on the community clinic and the needs of population it serves.

Over the years, with the evolution of the population being served through the community health centers that may come from a diverse range of

socioeconomic, educational, and cultural background, the health centers have evolved their services to offer public health services such as health promotion, education, advocacy and intervention, and case management (Taylor, 2004). In addition to broadening the type services unrelated to direct care, the type of staff at the community clinics has evolved from doctor and nurses to supportive staff such as social workers, health educators, and outreach workers. Social workers have been found to be the leading personnel that provide education and behavioral health services to patients in primary health care (Rowe, et al. 2017). A study on community health centers staffing patterns noted that community health centers that provide services to a large number of uninsured patients had fewer physicians and with this shortage there is a greater use of medical staffs who are not physicians (Ku, et al., 2015).

METHODS

Protocol

Qualitative action research was used to study the need of advance care planning education in Dallas County, Texas hospital community health centers. Individual face to face structured interviews were the method of data collection. Structured interviews are used when the researcher does not necessarily want to build a rapport and have additional meetings with the interviewee however is seeking to produce and compare data amongst respondents (Cohen, 2006). Patients in this study were visiting the community health center for scheduled appointments and those individuals escorting them at the time of appointment were considered as their caregivers.

Setting

The study was conducted in four (4) of the twelve (12) Dallas County Hospital Community Health Centers. The four community health clinics were chosen because they have a geriatric specialization unit who serve persons 65 years old and older. The community health clinics are centers that are utilized by persons of any age who live within a short distance to the centers who wish to receive medical treatment and other health related services.

Sample

A total of 102 respondents completed a survey on advance directives and care planning. Sixty four

(62.7%) patients, thirty seven (36.3%) caregivers and one (1%) staffer were randomly chosen. 49 % respondents reported their race as Latino, 42.2% were African American, 5.8% were White, and 3% were other (Chinese, Vietnamese). 69.6% primary language was English, 29.4% Spanish, and 1% other. The majority of the respondents (79.4%) reported that they did not have advance care plans written down.

Survey Instrument

The survey instrument contained 4 closed ended questions (with the opportunity to explain the selections) on Advance Care Planning and Advance Directives. This article was developed based on the four questions as well as written comments that were submitted in relation to the questions. Each respondent were instructed to answer “yes” or “no”.

The questions were as followed:

Do you know what Advance care Planning, Do you have Advance Care plans written down, Are you interested in learning about Advance Care Planning, and if interested would you like to learn about Advance Care Planning in a private group session.

Data Analysis

Qualitative data were analyzed using Thematic Analysis. Responses were closed ended and collected through a survey.

RESULTS

As indicated in Table 1, the majority of the respondents (73.5%) reported not knowing what Advance Care Planning is. 35% was Hispanic and 31% were African American (table 2). While 26.5% reported knowing what advance care plans were only 20.6% of those respondents reported having the plans written down. After completion of the survey it was learned that of those 26.5% (27) respondents who answered “yes, they knew what Advance Care Planning is”, about 6% (6) of the respondents really did not understand what ACP was.

80.4% of the respondents were interested in learning about Advance Care Planning with 19.6% reporting that they were not interested and 14% of the respondents who did not know what ACP was did not want to learn about it while 16% of those who reported that they had care plans written down were interested in learning about the subject although they had some learning experience with the topic.

Table 1: Survey Questions

	n	%	y	%
Do you know what Advance care Planning	75	73.5	27	26.5
Do you have Advance Care plans written down	81	79.4	21	20.6
Are you interested in learning about Advance Care Planning	20	19.6	82	80.4
If interested would you like to learn about Advance Care Planning in a private group session.	31	30.4	71	69.6

Table 2: Demographics of respondents

Ethnicity	n	%
African American	43	42.2
Hispanic	50	49
White	6	5.8
Other	3	3
Type	n	%
Patients	64	62.7
Caregivers	37	36.3
Staffer	1	1
Language	n	%
Spanish	30	29.4
English	71	69.6
Other	1	1

When asked the question “if interested, would you like to learn about Advance Care Planning in a private group session”?, 69.6% responded they preferred a private session while 30.4% mentioned that they did not want to learn privately. In the comment section, one respondent mentioned that they much rather have a group session, another responded that they rather get information over the internet so they would not feel pressured while several commented that a group setting was ok. Several respondents mentioned the location of the session and responded any location would be fine and another commented they would like the session in the privacy of their home and lastly one respondent mentioned that in the beginning the sessions, a group setting would be ok but if additional meetings were required they would rather it be one on one.

DISCUSSION

Patients who do have advance care plans written down were not prevalent in the study population (81%) although these patients were already established (had already been to the center before) at the community health center. In addition, in this population studied 73.5% did not know what advance care planning is and 14% was not interested in learning what it was.

These findings are consistent with previous studies. In a 2013 study on completion of Advance Directives amongst U.S. Consumers, Rao et al. identified 26.3% had an advance directive while 74.7% did not.

The study respondents ethnicity were majority Hispanic (49%), then African American (42.2%), White (5.8%), and 3% were of Asian descent. Of those respondents around 10% (11) African American and 10 % (10) Hispanic, and 0% were White reported that they have advance care plans written down. These findings of completion of advance care plans are contrary to studies that indicate that whites more so Hispanic or African American are likely to have complete advance care planning. Carr and Luth (2017) reported that rates of completion are low among African American and Latinos relative to Whites. Another study on the completion of advance directives among U.S. consumers also indicated completion of advance directives were amongst whites versus other ethnicities (Rao, et. al, 2014).

In 1990 the Patient Self Determination Act placed guidelines that stipulated any health care organization that received Medicare and Medicaid reimbursement to provide written information on Advance Directives (Leod-Dyess, et al., 2014). Dissemination of the information most likely occurred during a visit and provided with discharge papers that patients may or may not have read without a discussion from their provider or a nurse. Due to low number of completions research was conducted as to why the numbers remained low amongst the U.S. population. Some of the noted reasons for the lack of completion was patients were not aware of ACP and another reason were that providers were not being reimbursed. In 2016, rules changed and providers gained the ability to be reimbursed for the discussion on ACP yet the number of completions continues to remain low.

After polling patients and caregivers that visit the Dallas County Hospital community health centers, this study highlights that people still do not know or

understand what Advance Care Planning is and providing education within the health centers may assist with increasing the knowledge on the topic which is consistent with a study by Leod-Dyess, et. al (2014), who noted that before any health crisis there should be a discussion on ACP beginning in the office of an individual primary care, an environment that is conducive to families, or in an outpatient setting.

With the ability to be reimbursed for the discussion on advance care planning, it is assumed that the discussion has occurred for patients who are established with the centers however this study shows that the majority of the current patients and their caregivers of the polled centers didn't know what it was.

LIMITATIONS

The study was conducted on a sample of patients and caregivers who were visiting the clinics seeking some form of health care. The majority of the clinics that were visited are located in improvised communities within Dallas County. There were no controls for issues of competency, literacy, or cognitive impairment of the patient and/or their caregiver. Further study can focus on patients living within a higher socioeconomic status, polling the additional Dallas county hospital community health centers that are part of a community that serve a more diverse population, in addition to studying the most common place patients/caregivers obtain information on Advance Care Planning and/or complete the plans, and if provided, will structured educational classes on ACP at the health centers increase the knowledge of patients/caregivers about the topic.

CONCLUSION

Community Health Centers has been a place in which services and resources were gained by individuals that may not have otherwise received or be aware of, especially for those that are in a lower socioeconomic status. With community health centers being a location that host community initiatives, educational information and awareness on a specific topic, and providing additional other social service resources can be gained at a community health center. This study researched the question as to if structured education on advance care planning particularly advance directives should be provided in the Dallas County hospital community health centers.

The results show that the Dallas County Hospital Community Health Center patients and their caregivers in this study did not know what advance care planning was and most of those persons that were surveyed did not have any advance care plans written down. Most of those surveyed were interested in learning about ACP with a few of those that did not know what it was, being uninterested in learning about it. The preference of learning about ACP was in a private session versus being in a group, this preference may have to do with the concern of discussing private information in an open setting.

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