

Exploration of factors that influence advance care planning for primary care patients

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Abstract

The purpose of this exploratory descriptive research study is to explore the individual factors that influence health care decisions in a small sample of primary care patients who have received advance care planning education through the State Innovation Model Grant in Rhode Island. Both quantitative and qualitative data was gathered from a voluntary 10 question participant survey. This survey research aimed to answer the following research questions: What are the individual, environmental and behavioral factors that influence healthcare decisions at end-of-life? How do individuals, in their own words, describe the thought process used for making decisions about advance care planning? A 38% response rate was achieved. Results revealed that education about end of life care and family were the most consistently reported elements which helped make choices for preferred care at end of life. Two major themes emerged, control over self and family, and sharing of experiences that impact decision making for care at end of life. Awareness of elements that influence preferences for care provide valuable insight into the thought processes that frame healthcare choices for end of life care and identify barriers and facilitators that influence end of life planning. Knowledge of this information can guide program development, policy and procedures around advance care planning.

Keywords: advance care planning, decision making, end of life care, health behavior, communication, primary care

Copyright Page

There were no copyrighted materials utilized within this project.

PREVIEW

Table of Contents

Abstract.....	2
List of Tables.....	50
List of Figures.....	52
Introduction.....	8
Problem Statement.....	8
Purpose of the Project.....	9
Clinical Question.....	9
Review of the Literature.....	9
History of Advance Care Planning.....	9
Definitions & Legislation.....	10
Barriers to Advance Care Planning.....	12
Financial Implications of Advance Care Planning.....	15
National Education Efforts.....	16
Significance to Practice.....	18
Theoretical Framework.....	20
Methodology.....	22
Participants.....	22
Setting.....	23
Tools.....	23
The Intervention and Data Collection.....	23
Risks.....	25

Protection of Subjects.....	25
Confidentiality.....	25
Benefits.....	25
Analysis.....	25
Findings from Quantitative Analysis.....	25
Findings from Qualitative Analysis.....	27
Control over self and family.....	28
Decision making for care at end of life.....	28
Discussion.....	29
Limitations.....	31
Significance and/or Implications.....	33
Goals for Future Research.....	35
References.....	37
Appendix A.....	45

List of Tables

Table 1. Participant Characteristics.....	50
Table 2. Qualitative Data: Coding Categories and Description of Themes.....	59

PREVIEW

List of Figures

Figure 1. Quantitative Results Question 1.....	52
Figure 2. Quantitative Results Question 2.....	53
Figure 3. Quantitative Results Question 3.....	54
Figure 4. Quantitative Results Question 4.....	55
Figure 5. Quantitative Results Question 5.....	56
Figure 6. Quantitative Results Question 6.....	57
Figure 7. Quantitative Results Question 7.....	58

Exploration of factors that influence advance care planning for primary care patients

Only one in three people have discussed their preferences for serious illness care with their family and one in ten with their healthcare provider (Coalition to Transform Advanced Care, 2013). The Centers for Disease Control and Prevention (2017) report that 70% of Americans are without an advance care plan. There is a great opportunity to engage, educate and empower patients to communicate their preferences for care to their family and healthcare providers. The Institute of Medicine (IOM) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (2014), has called for a transformation in how we care for the dying with emphasis on enhanced communication and documentation of healthcare wishes. A key recommendation is to normalize end-of-life conversations through engagement of persons and families in care planning throughout the trajectory of health (Institute for Healthcare Improvement, 2014). This responsibility falls upon all providers, including primary care clinicians, hospitalists and even specialists, in both the acute and subacute settings. Education about the importance of advance care planning (ACP), improved communication processes and documentation of wishes across the continuum can lead to care that aligns with patient's wishes improving the quality and value of care (Bernacki et al., 2015). Consumer and clinician education, as well as redesign of current workflow processes, may contribute to improved knowledge around the importance of ACP resulting in better documentation and subsequently care that aligns with patient's values and preferences.

There is limited research exploring the individual-specific factors that influence healthcare decision making at end of life. There is a need to understand how individuals formulate preferences for end of life care and identify the important elements that influence these choices. Recognizing what matters to individuals beyond the physical, disease-specific medical

care can provide opportunity to align end of life care with patient's values. The purpose of this exploratory descriptive study is to understand the individual factors that influence health care decisions in a small sample of primary care patients who have received advance care planning education through the State Innovation Model Grant. The research questions are: 1) What are the individual, environmental and behavioral factors that influence healthcare decisions for end-of-life care? And 2) How do individuals, in their own words, describe the thought processes used for making decisions about advance care planning? This study aims to explore individual factors that influence decisions and preferences for end of life care. Findings from this study may offer opportunities to enhance the way we engage, educate and empower patients to communicate their preferences for care at end of life.

Literature Review

The literature search was conducted using the following databases: CINAHL, PubMed, EBSCOhost, and Cochrane Library. Search terms included: advance care planning, decision making, end of life care, health behavior, communication, primary care.

History of Advance Care Planning

The Patient Self-Determination Act (1990) was passed by the United States Congress to inform patients of their rights regarding decisions toward their own medical care, and ensure that these rights are communicated by the healthcare provider. This federal law protects individuals' right to accept or reject medical or surgical treatments as instructed by their written advance directive. Additionally, the law allows for the appointment of a durable power of attorney in the event that the individual becomes incompetent (Kelley, 1995). Despite the fact that this law was passed almost three decades ago, completion of advance directives remains considerably low. Approximately three-quarters of the population do not have an advance care plan (Centers for

Disease Control and Prevention, 2017). Rao, Anderson, Lin and Laux (2014) identify the primary reason is lack of awareness. Lack of discussion and documentation of ACP can result in care that does not align with patient wishes. A retrospective analysis of Medicare beneficiaries from the National Health and Aging Trends Study (NHATS) revealed one in eight bereaved respondents reported care in the last months of life was inconsistent with patients' wishes and was associated with worse ratings of care, pain management and communication with clinicians (Khandelwal et al., 2017). Care at the end of life is often wrought with multiple transitions and high utilization of intense treatment that is not consistent with patient's wishes. Concerns exist as to how well we are matching medical care to individual values and preferences.

Effective communication enhances, not only end of life care, but quality of life throughout the trajectory of illness (Bernacki & Block, 2014). In the past decade, there has been a wave of national attention on the importance of ACP throughout the trajectory of illness as an essential aspect of person-centered care (Institute for Healthcare Improvement, 2014). Advance care planning acknowledges that individuals' preferences often evolve as their health care status changes (Mackenzie, Smith-Howell, Bomba, & Meghani, 2018). Early goals of care conversations are associated with better quality of life, positive family outcomes and reduction in non-beneficial care at end of life resulting in reduced costs (Bernacki et al., 2015). This becomes increasingly important as we move away from fee for service and into an era of value-based care.

Definitions & Legislation

Many definitions of advance care planning exist throughout the literature. A recent Delphi survey of palliative care experts defined ACP as a process of care “ that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and

preferences regarding future medical care” (Sudore et al, 2017a, p. 821). ACP allows for patients and families to consider and express preferences for care that corresponds with their values through a facilitated discussion, by any treating clinician, intended to be updated as circumstances change (Bond et al., 2018).

While ACP speaks to the process of care, an advance directive is a legal document completed and signed which provides guidance for medical and health care decisions in the event the person becomes incompetent to make such decisions (Merriam-Webster, 2018). Appointing a durable healthcare power of attorney or proxy decision maker is an important aspect of the advance directive. The healthcare power of attorney form designates a surrogate to complete decision making in the event the individual is unable to make his or her own health decisions (Rhode Island Department of Health, § 23-4.10-2, 1986). If appropriate, a Medical Order for Life Sustaining Treatment (MOLST) document can also be completed which clarifies wishes for resuscitation, crosses home and healthcare settings and can be translated into inpatient code status orders with a patient’s affirmation (Bond et al., 2018). In January 2014, the Rhode Island Department of Health passed legislation enacting the MOLST form as a portable healthcare order for terminally ill patients (Rhode Island Department of Health, R23-4.11-MOLST, 2013). The MOLST order can be used to refuse or request treatment and is completely voluntary. In the state of Rhode Island, this form can be completed by a physician, nurse practitioner or physician’s assistant in any healthcare setting (Rhode Island Department of Health, R23-4.11-MOLST, 2013). This legislative change is an example of Rhode Island’s commitment to honoring patient’s preferences for care.

Nationally, the Centers for Medicare and Medicaid Services (CMS), reimburse clinicians for ACP documentation because these crucial conversations result in improved patient

satisfaction with care, improved patient and family quality of life, and receipt of medical care that aligns with patient's wishes. (Institute of Medicine Report, 2014). Effective January 1, 2016, CMS pays for ACP under the Medicare Physician Fee Schedule (MPFS) and the Hospital Outpatient Prospective Payment System (OPPS). The Current Procedural Terminology (CPT) codes are 99497 (first 30 minutes of advance care planning, when meeting or exceeding 16 minutes) and 99498 (each additional 30 minutes of advance care planning, when meeting or exceeding 46 minutes). Medicare will pay for ACP discussions when medically necessary and as a part of the annual well visit. There are no limits on the number of times ACP can be reported for a given individual (Department of Health and Human Services, Center for Medicare & Medicaid Services, 2016). Additionally, "incident to" billing applies to ACP conversations in the outpatient setting. For example, a licensed clinician (social worker or nurse) can provide ACP education and initiate the discussion and the provider can debrief afterwards and bill for the total time spent. The CMS policy change provides incentives to clinicians from any specialty to discuss patients' views on quality of life and care preferences (Lakin et al., 2017). The importance of ACP conversations is recognized as an essential part of quality value-based care.

Barriers to Advance Care Planning

There are a number of well-documented reasons that exist as barriers to advance care planning. They include timing, age, procrastination, health status, knowledge deficits, concerns for others, ownership of who is responsible to start the discussion, appropriate setting for ACP conversations, discomfort, or expectations that family members will make end of life decisions (Crisp, 2007). Specific patient, as well as provider, reasons are responsible for the low completion rate of advance directives that exist today. A dated but pertinent study by Crisp (2007) revealed three major themes which emerged from qualitative interviews seeking to