



Patient and nurse perspectives on advance care planning in acute care

Priscilla K. Gazarian (PhD, RN) (Associate Professor)*, Julie Cronin (MBA, RN, CCRN),
Kayla M. Baker (MS, RN), Barbara J. Friel (MS, RN, CCRN)

University of Massachusetts Boston, College of Nursing and Health Sciences, 100 William T. Morrissey Blvd., Boston, MA 02125-3393, United States



Our population worldwide is aging and chronic disease is prevalent. Three out of four persons over the age of 65 have more than one chronic condition (National Center for Chronic Disease Prevention and Health Promotion, 2015). Technological advances are capable of prolonging life almost indefinitely. Current literature reflects well-documented changes in causes of death and patterns of care at the end of life. Because of biomedical advances, there has been a decline in the number of deaths from heart disease by 10.8% in the years between 2000 and 2015, and a rise in the number of deaths from Alzheimer's disease and related dementias (Aldridge & Bradley, 2017). These changing demographics of living longer with multiple chronic illnesses have made advance care planning (ACP) a prominent issue in our society.

ACP conversations are meant to help persons make their goals and preferences for future care known. Most people state that they want to die at home; however, the pattern of dying in the United States is quite the opposite. Frequently individuals experience multiple transitions in care at the end of life. These care transitions often include admission to a hospital, an intensive care unit (ICU) or nursing home (Aldridge & Bradley, 2017). Care transitions are often associated with invasive and costly interventions. Among Medicare patients in the last month of life, 18.3% had surgery and 29.2% were admitted to an ICU (Duncan, Ahmed, Dove, & Maxwell, 2019; Marik, 2015). Improved ACP conversations would support goal concordant care across the transitions.

While ACP conversations can be emotional and unpredictable, they are an important way for patients to exercise their autonomy. These conversations allow patients an opportunity to establish and document personal values, goals, preferences, and have been associated with improved survival, quality of life and family member coping (Institute of Medicine, 2015). ACP is the completion of an Advance Directive (AD) including the appointment of a medical decision maker (health care proxy) and discussion and documentation of health care goals and preferences with family members and the health care team (Rietjens et al., 2017). Despite the benefits of ACP, conversations are not consistently happening across health care settings and in some cases resultant documentation is incomplete and unreliable. Barriers to implementation include competing care demands and allocating time to have a meaningful conversation. Yet, using specially prepared clinicians

and a structured approach including the use of a decision aid facilitates successful ACP (Lund, Richardson, & May, 2015).

1. Background

Increasing the AD completion rate has become a national priority because this documentation supports patient-centered, goal congruent care while reducing the overall cost of health care (Yadav et al., 2017). However, only one in three adults has completed an AD and completion rates have remained steady over decades (Yadav et al., 2017). Recent reports demonstrate the reasons for not completing an AD are non-specific: 49% haven't gotten around to it and 27% never considered it (Hamel, Wu, & Brodie, 2017).

The Patient Self Determination Act (PSDA) of 1990 was the first regulatory measure enacted to address ACP (US HR4449, 1990). The PSDA requires medical facilities that receive Medicare or Medicaid funds to provide information about ADs (Glick, Cowart, & Smith, 1995). Though living wills had been previously available prior to the PSDA, this legislation was intended to educate the public and encourage the use of ADs (Hunsaker & Mann, 2013). The PSDA requires that patients: be informed of their right to complete an AD, have the existence of an AD documented in the medical record, and be provided respectful and impartial care regardless of personal choices (Glick et al., 1995). Since the inception of the PSDA, AD completion rates have not improved, nor has the legislation been effective in improving ACP outcomes (Baker, Einstadter, Husak, & Cebul, 2003; Kelley et al., 2011). In 2016, Medicare began allowing physicians to bill for ACP conversations. Yet the PSDA experience shows that regulatory measures alone are not likely to have an impact on the process or completion of ACP (Dresser, 2016).

Although the PSDA was signed into law, momentum for impact was lost during implementation. The process has been systematized to a yes-no question at admission with little opportunity for patient education and information, one of the law's stated aims. Most would agree that ACP should be completed in the primary care setting, not the high-stress environment of acute care (De Vleminck, Houttekier, Deliens, Vander Stichele, & Pardon, 2016). As noted above, motivating patients to complete ACP remains a challenge. A hospital admission represents a

* Corresponding author.

E-mail addresses: Priscilla.Gazarian@umb.edu (P.K. Gazarian), Julie.Cronin001@umb.edu (J. Cronin), Kayla.baker001@umb.edu (K.M. Baker), Barbara.healy001@umb.edu (B.J. Friel).

<https://doi.org/10.1016/j.apnr.2019.151203>

Received 7 January 2019; Received in revised form 6 June 2019; Accepted 18 October 2019
0897-1897/ © 2019 Elsevier Inc. All rights reserved.

window of opportunity for action for two reasons. First, admission to a hospital likely means an acute change in health status such that ACP is no longer a hypothetical future event. In these acute cases, a previously completed AD may no longer be applicable. Second, acute care settings are often the place where lifesaving interventions are implemented.

Studies on the use of educational resources and decision aids to support a structured approach to the completion of ADs have shown promising results. PREPARE, a website to support an individual's decision making and communication about ACP demonstrated improved engagement in the ACP process (Sudore et al., 2014). Similar results have been seen with other resources such as Respecting Choices ACP Program (Overbeek et al., 2018), My Gift of Grace or Hello (Van Scoy et al., 2017), and the Five Wishes (Wickersham, Gowin, Deen, & Nagykaladi, 2019) to name a few. However, these resources are rarely used in hospital settings, and many nurses are not aware of their existence.

This study does not address the barriers and facilitators to ACP in general; rather we aim to understand how to better implement the use of patient education resources or decision aids into the acute care hospitalization and workflow. The American Nurses Association supports the nurse's role in ACP conversations (American Nurses Association, 2010). Additionally, the Hospice and Palliative Nurses Association believes that nurses should be accountable to facilitate patient decision making, educate stakeholders, and to integrate ACP into practice routinely (Hospice & Palliative Nurses Association, 2017). The nurse's role in ACP encompasses advocacy and education. Additionally, nurses can serve as mediators in the ACP process between patients and families and patients and the health care team (Ke, Huang, O'Connor, & Lee, 2015). While there are many educational resources and decision aids available to support nurses in educating patients and families about ACP (Gazarian et al., 2019), they are underutilized in acute care. Therefore, the aim of this research is to describe the challenges and opportunities perceived by patients and nurses in the implementation of ACP processes and educational resources or decision aids into acute care.

2. Methods

2.1. Design

The purpose of this qualitative descriptive study was to describe the challenges and opportunities perceived by patients and nurses in the implementation of ACP processes and educational resources or decision aids into acute care. A qualitative descriptive methodology was used to provide a direct description and summary of the current implementation of ACP processes and educational resources or decision aids in the acute care setting (Kim, Sefcik, & Bradway, 2017).

An implementation science framework, Normalization Process Theory (NPT) provided a framework for the analysis of the data. Implementation science aims to explain what works and why, when trying to implement practice changes (Nilsen, 2015). NPT explains how individuals and groups implement new interventions or technologies into practice (May et al., 2011, 2015)

NPT includes four constructs, each with four sub-constructs, that characterize the actions or work that people do related to a particular practice as shown in Table 1. The four constructs include 1) *coherence*, or making sense of the process, 2) *cognitive participation*, or who performs the process, 3) *collective action*, or how does the process get performed, and 4) *reflexive monitoring*, or how is the process appraised. Implementation science frameworks can guide data collection, data analysis and also help report study findings. In this study, we used NPT to inform and guide our coding approach by coding the data to NPT constructs.

2.2. Sample and setting

We sought two stakeholder perspectives through four focus groups conducted between August and December of 2017. We conducted two focus groups with registered nurses and two focus groups with patients. We recruited a convenience sample of acute care nurses by requesting participation through a nursing practice council meeting. The participants in this group were likely expert nurses. Because of this perceived expertise, we decided to augment with snowball sampling and conduct an additional focus group of nurses to ensure we obtained an accurate description. The data from the second group of nurses was similar to the first group and it was determined that no additional information was revealed (saturation) (Saunders et al., 2018). Additionally, we conducted two patient focus groups. We recruited a convenience sample of community-dwelling elders through a university-based learning in retirement program. To ensure sufficient variation of perspectives, we recruited a second convenience sample of patient stakeholders from the Center for Patients and Families at an academic medical center. The nurse participants and patient stakeholders were all from one institution, a large academic medical center in the northeast, while the community-dwelling elders were affiliated with an urban university in the northeast.

2.3. Instrumentation

A nurse researcher with expertise in qualitative research and nursing care of acutely ill adults developed the semi-structured interview guide based on current literature and clinical experience. Nurses with experience in acute care nursing reviewed the interview guide for face and content validity. Focus group questions addressed general knowledge, the ACP process, and educational resources or decision aids to support ACP.

2.4. Procedures

At the start of each focus group, participants completed a demographic questionnaire. Participants provided written informed consent and received a \$50 gift card as compensation for their time. The university and medical center institutional review boards approved the study. The focus groups were facilitated by the PI with assistance from research assistants (RA). The focus groups were audio recorded and notes were taken by the RAs. Following verbatim transcription, transcripts were imported into Atlas Ti (version 8.3.1) for coding.

2.5. Analyses

Team members (PG and JC) read all transcripts to become familiar with the transcripts as a whole. Initial themes were identified by two researchers (PG, JC) and a preliminary codebook was created. The codebook was applied to transcripts using Atlas Ti. Transcripts were coded line by line by PG and JC in Atlas Ti. Differences in interpretation of the categorization of the themes and any emergent themes were resolved through discussion until consensus was achieved. Codes were then mapped to the constructs and sub-constructs of NPT. Because the interview guide was open-ended and not constructed based on the NPT, not all sub-constructs of the NPT constructs were mapped to the data.

2.5.1. Trustworthiness

Lincoln and Guba's (1985) methods of credibility, transferability, dependability, and confirmability were foundational in demonstrating the trustworthiness of the data. The research team employed prolonged engagement in the context culture of the setting where data was collected. Peer debriefing was conducted after the focus groups and the research team maintained a careful audit trail of data.

Table 1
NPT constructs and sub-constructs.

Construct	Sub-construct
Coherence sense-making work that people do individually and collectively when they are faced with the problem of operationalizing some set of practices	Differentiation: participants distinguish the intervention from current ways of working Communal specification: participants collectively agree about the purpose of the intervention Individual specification: participants individually understand what the intervention requires of them Internalization: participants construct potential value of the intervention for their work
Cognitive participation relational work that people do to build and sustain a community of practice around a new technology or complex intervention.	Initiation: key individuals drive the intervention forward Legitimation: participants agree that the intervention should be part of their work Enrollment: participants buy into the intervention Activation: participants continue to support the intervention
Collective action operational work that people do to enact a set of practices, whether these represent a new technology or complex healthcare intervention.	Interactional workability: participants' perform the tasks required by the intervention Relational integration: participants maintain their trust in each other's work and expertise through the intervention Skill set workability: the work of the intervention is allocated appropriately to participants Contextual integration: the intervention is adequately supported by its host organization
Reflexive monitoring appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them.	Systemisation: participants access information about the effects of the intervention Communal appraisal: participants collectively assess the intervention as worthwhile Individual appraisal: participants individually assess the intervention as worthwhile Reconfiguration: participants modify their work in response their appraisal of the intervention

3. Findings

A total of eight Registered Nurses and 11 patients (community-dwelling elders or patient stakeholders) participated in the four focus groups. The mean age of patient participants was 69 years, and the mean age of the nurse participants was 30.7 years. The majority of participants were female (78.95%), white (84.21%), and college-educated (89.47%) Table 2 shows the demographics of the focus group participants. The main themes are organized according to NPT constructs presented in Table 3 and described below.

3.1. What is the process of ACP in acute care settings (coherence)?

ACP is a dynamic, difficult, confusing but valuable process of making one's wishes known. Four themes were identified related to the NPT construct of coherence. ACP is 1) unique, 2) not well understood or defined, 3) a dynamic decision-making process, and 4) needs to be individualized.

Table 2
Demographic chart.

	Community dwelling elders	Patient stakeholders	RN Group 1	RN Group 2	Total
Number of participants	6	5	3	5	19
Age mean (range)	69.5 (63–74)	68.6 (59–76)	32(27–39)	29.4(26–33)	0.21% white
Gender					
Female n (%)	6 (100)	3 (60)	3 (100)	3 (60)	15 (78.95)
Male n (%)	0	2 (40)	0	2 (40)	4 (21.05)
Ethnicity					
Not Hispanic/Latino n(%)	6 (100)	5 (100)	3 (100)	5 (100)	19 (100)
Race					
Black/African American n (%)	0	1(10)	0	2 (40)	3 (15.79)
White n (%)	6 (100)	4 (80)	3 (100)	3 (60)	16 (84.21)
Education					
High school n (%)	1 (16.6)	0	0	0	1(5.26)
Associate n (%)	0	1 (10)	0	0	1(16.6)
Bachelor's n (%)	1(16.6)	2 (20)	3 (100)	5 (100)	11 (57.89)
Master's n (%)	4 (66.67)	2 (20)	0	0	6 (31.58)

3.1.1. Unique because of the seriousness of, or discomfort with the topic

Participants agreed that ACP is a process that addresses defining and ensuring an individuals' care preferences. Through the focus groups, ACP was seen as a dynamic process, as people change their mind as their life course and illness evolves. A patient stakeholder commented that concern with the process exists because, "It's not something you need to do, and [the perception is that decisions made are] just set in stone," (patient stakeholder M1). Participants also uniformly perceived the conversation about future care as a difficult subject that may be potentially upsetting. Participants discussed a range of emotions associated with the topic including fear, uncertainty, anger, "fear of the unknown"(nurse M1), compassion, "you want to be addressed with sort of a personal concern and compassion," (patient stakeholder F3), and hope, "I never want to walk in and offer some of these things and take away your hope. I think that's my biggest fear," (nurse M2). Despite acknowledging that end of life issues are an emotional topic to discuss, the participants regarded these conversations as a way to respect a person's dignity and autonomy and therefore a valuable process, "as long as you try to do it

Table 3
Main Themes Organized According to NPT Constructs and Subconstructs.

NPT construct	Theme mapped to subconstruct	Exemplar quote
Coherence: what is the process of ACP in adult acute care settings	Unique because of the seriousness of or discomfort with the topic (differentiation and internalization)	“It wasn’t that I was ready to do it, but because of the challenge that I had of being faced with cancer, I thought that was the right thing to do. I didn’t really want my children to be in a situation where they had to make a lot of decisions and really not know how I felt about it.” <i>Patient Stakeholder M1</i>
	Not well understood or defined (communal specification)	“People don’t know what an advanced directive is.” <i>Patient Stakeholder F7</i>
	Is a dynamic, decision-making process (individual specification and internalization)	“You can change your wishes... that’s part of the problem with putting this all down on one piece of paper.” <i>Patient Stakeholder M2</i>
	Needs to be individualized to the patient and their situation (individual specification)	“Would you like to talk about it? Some people might not want to talk about it,” <i>Patient Stakeholder F1</i>
Cognitive participation: who should be involved ACP?	Normalize ACP to involve everyone (activation and legitimation)	“We talked about putting posters around to, one, normalize the conversation. But I think they would go a long way to empower people too because there’s that big push about it’s okay to ask if your provider has washed their hands on the way in. Those are all over the hospital, so why not, it’s okay for you to initiate the conversation about advance care planning?” <i>Patient Stakeholder M2</i>
	Is a collaborative process including the patient, health care proxy and health care team members (enrollment and initiation)	you’re just asking about advanced directives, and if questions about risks of surgery come up, that’s a cue that the patient needs to speak with the surgeon.” <i>Patient Stakeholder M1</i>
Collective action: how is ACP performed	Process requires clinical knowledge and judgment by providers (relational integration)	“I feel like it’s hard for us to breach these questions with our patients on admission because they’re so anxious to begin with. They’re coming in for transplants, and they’re so overwhelmed, and here I am asking about end of life.” <i>Registered Nurse F3</i>
	Materials are not accessible (contextual integration)	“Right now we have no process, no materials.” <i>Registered Nurse F5</i>
	Process is disjointed in E H R, no workflow for follow up (contextual integration)	“I check the box or I find the scanned item, I print it out, and I put it in the chart...That’s kind of where it ends.” <i>Registered Nurse F6</i>
Reflexive monitoring; How is ACP assessed or evaluated?	Avoidance is common (individual appraisal)	“So this is a very sensitive issue, and without that sensitivity, you’re not going to get the results that you’re looking for.” <i>Patient Stakeholder M1</i>
	Lost opportunities (reconfiguration) Workarounds Reduced to task completion time pressure	“just a day late, a dollar short... because everyone’s emotions are so high, and the patient may no longer even be able to express their wishes, so it’s too late at that point.” <i>Registered Nurse F2</i>

with dignity and respect and hoping that they’re open enough to really embrace the conversation,” (patient stakeholder M1).

3.1.2. Not well understood or defined (communal specification)

Although there was a broad conceptual agreement on ACP, the specifics of the process were less clear. Both nurses and patients raised questions about the terminology and legality of documents. Additionally, terminology was a source of confusion. Patients emphasized the importance of using plain language such as, “Do you have some who can speak for you?” instead of, “Proxy,” (patient stakeholder F1), because “English is not everybody’s first language, and not everybody has a Ph.D.,” (patient stakeholder F3). Nurses reported that confusion often resulted from knowledge gaps regarding specific terminology. Nurse participants commented that among members of the health care team there was no common understanding of terms such as AD, Health Care Proxy and Living Will.

All focus groups cited misunderstandings and misperceptions regarding the legalities of ACP documentation. Nurses discussed having to witness some forms (Health Care Proxy) but not other forms (Advance Directives). Further, while the clinical staff is required to witness the signature for the appointment of a Health Care Proxy (HCP), there is no requirement that the HCP acknowledges their appointment, a key factor in the process. A nurse asked,

How are we supposed to know that this patient has talked to their proxy and agreed. [The proxy doesn’t] have to sign...If they changed that paperwork, then you would at least know that those two people

met at some point and at least the words ‘health care proxy’ were exchanged

(nurse F6)

3.1.3. Is a dynamic, decision-making process (individual specification and internalization)

Both patients and nurses recognized that writing down goals and preferences for future care requires time to reflect and decide and that those preferences change over time. Nurses reflected that asking patients on admission to the hospital could set people up to default to invasive care, “People have so much else going on that they are nervous to make any commitment one way or the other, and so they always default to full code and aggressive care,”(nurse M2).

Accessible educational resources and decision aids and educational material are paramount to the ACP process as these resources help patients through the needed reflection and decision-making. One nurse explained that having education material allowed him to tell the patient,

You don’t need to answer us right this second, you know? And so, it looks like educational material that somebody could just read through on their own time and get some more information,” and “I feel like they sometimes feel like they need to provide an answer right then. It’s like no, this is serious stuff, you can take some time. Think it over, talk it over with your family

(nurse F6)

3.1.4. Needs to be individualized to the patient and their situation (individual specification)

Because of the dynamic nature of these decisions, individualizing the approach is essential. Patients offered concrete suggestions for working with individual patients, “*Different people have different needs and come from different backgrounds, as to whether or not they need guidance or not,*” (patient stakeholder F1). Patients suggested assessing openness and learning style, “*ask the person how they want to receive information,*” (patient stakeholder F3). Individual preferences vary, as one nurse explained, “*a lot of us assume people want to get home to die, but I had one patient... and she was like, ‘Home is where happy memories are, and I want that [to stay that way],’*” (nurse F3).

3.2. Who should be involved ACP (cognitive participation)

Two themes were identified related to the NPT construct of cognitive participation: 1) normalize ACP to involve everyone and 2) ACP is a collaborative process including the patient, HCP and health care team members (enrollment: participants collectively contribute).

3.2.1. Normalize ACP (initiation)

Both nurse and patient participants related the importance of talking about ACP, removing the stigma associated with end of life discussions. Nurse participants discussed instituting a broad approach where all patients would be asked about end of life decisions regardless of diagnosis or condition. One nurse suggested asking all patients “*since you're in the hospital, we need to know your wishes,*” (nurse M2). Nurses recommended that having more educational materials and decision aids available on the unit would be useful and help normalize the topic, “*Hand [the material] out to everybody on admission, when you ask that question, here's some materials, if you want to talk about it later or at any time, I'm available,*” (nurse F7). An alternative suggestion was to make the materials available on the unit either in the patient rooms or in a common area so that patients could freely select materials based on their interests or needs.

Patients asked why ACP isn't more prominent, suggesting a social advocacy campaign utilizing city buses or that, “*there should be a poster in every doctor's office,*” (patient stakeholder F1). Patients discussed ACP as a personal responsibility, “*We have patient responsibilities...another thing should be to have a healthcare proxy, I mean, that should be a patient responsibility,*” (patient stakeholder F1). One patient suggested a regulatory change to promote ACP completion, “*I think we should change the Medicare rules. You can't go on Medicare until you finish your advance directive,*” (patient stakeholder M2).

3.2.2. ACP is a collaborative process including the patient, care partners, and health care team members (enrollment and legitimation)

ACP conversations require collaboration between the patient, their HCP, and the health care team. Patients have an essential and central role in the ACP process, as these decisions are to reflect the patient's individual wishes. Each of these parties needs to be prepared to participate in the process.

Patients discussed the patient's role in the conversation. Some patients are not ready to have this conversation while others are highly empowered to take charge. “*And she was not willing to discuss [ACP], was not willing to talk about it, because she had made up her own mind, this was not her time,*” (patient stakeholder M1), describing his experience with a family member with advanced cancer), contrasted with another patient, “*I try to always remember when I have my annual physical with my primary physician to have those discussions, got to make myself like a little checklist to discuss things, and then go from there,*” (patient stakeholder M2).

The HCP becomes a prominent care partner through the process. Despite the importance, participants discussed situations in which patients want little involvement in selecting and communicating with the HCP. A nurse explained,

I've had patients that they have never had a conversation about [end of life wishes]. The person is literally dying in front of us, and [the health care proxy says] ‘I don't know what to do,’ and it's so tough to watch because we prolong things for weeks and weeks, and then we finally decide to stop

(nurse M1)

Alternatively, another nurse explained, “*I also find a lot of patients that designate a health care proxy and think that means they don't have to make a medical decision ever again,*” (nurse M2). Nurse and patient participants acknowledged that ACP conversations should ideally be conducted in primary care with a provider the patient knows and trusts. Both nurses and patients agreed that having a relationship with or being known by the provider was an important factor in ACP. To the study participants, being in a relationship with the provider was more important than the provider's role or discipline. In some cases, a nurse may be in the best position to initiate these conversations because the nurse has been with the patient and family for 12 hours, and the physicians come in and out for short visits. Yet, not all nurses were prepared to have these conversations. Social workers were identified as highly skilled in ACP, especially in complex situations, a nurse explained, “*Our social workers are great, they are so involved, and they pretty much have the answer to everything. And if they don't, they typically know whom to call,*” (nurse F5). Nurses need to be aware of their resources, to know how and when to bring other members of the health care team into the conversation in the event that the patient has questions about risks or disease prognosis.

3.3. How does ACP get accomplished (collective action)?

Three themes were identified related to the NPT construct of collective action: 1) the need for clinical knowledge and judgment, 2) inaccessible material, and 3) a disjointed electronic health record (EHR) process.

3.3.1. ACP requires clinical knowledge and judgment by nurses

Given the sensitivity of the subject and the variability of patient readiness, accomplishing ACP requires nurses to employ clinical judgment as to how and when to initiate conversations. As stated above, normalizing the conversation is important. The presence of an AD is routinely assessed on admission. This assessment supports normalizing the process and protects a person's right to self-determination. Yet, it can be difficult to have a substantive conversation about ACP on admission when patients are often anxious and acutely ill, “*It's hard for us to breach these questions with our patients on admission because they're so anxious to begin with,*” (nurse F7). Nurses spend large amounts of time at the bedside with patients and families and are in a position to assess patient and family cues to readiness for these conversations. This intimate access allows nurses to find teaching moments in a natural way or find times in conversation when patients are ready.

3.3.2. Materials are not accessible

Both patient and nurse participants reported that having materials readily available would help initiate conversations and bolster follow-up conversations with patients. As this nurse participant states, “*I didn't know that any of these [materials] were out there as a resource. And we deal with the end of life every shift. So, I think there's obviously a lack of education regarding resources for patients,*” (nurse F6).

All focus groups appreciated to learn that ACP resources are available through various modalities (e.g., printed materials, internet websites, etc.). Nurses suggested having posters around the unit and in family rooms, information on the educational tv system, as well as different modalities of decision aids. Nurses favored workbooks that could be completed independently by patients and families such as the Five Wishes from Aging with Dignity or The Conversation Starter Kit from the Conversation Project. Some nurses felt that internet programs

may have some utility as this nurse reports, “Because they already have conversations, and the family comes out with the iPad and they ask me all these questions,” (nurse F6).

3.3.3. The process is disjointed in the electronic health record, no workflow for follow up

Nurses described an electronic health record (EHR) process that is poorly implemented and disjointed. Assessment of the presence of an AD is viewed as one of the many ‘checkboxes’ on an admission assessment. Nurses describe workarounds to ensure the AD status is accurately reflected in the EHR. At this hospital, the patient is asked about AD on admission. If the patient does not have their AD with them, they will be asked to complete another one which is then added to the EHR. However, if one is already on file in the EHR the nurses reported that they may not address the topic with the patient since the AD is documented.

The nurse participants stated that if the patient wants more information about AD, a standard handout is provided. Nurses were not aware of any additional educational materials that could be provided to the patient to assist them in the ACP process. After completing admission forms, there is no workflow to follow-up with patients about revisiting their current ACP or to provide additional support.

3.4. How is the process of ACP understood (reflexive monitoring)?

Two themes were identified related to the NPT construct of collective action: 1) avoidance and 2) lost opportunities.

3.4.1. Need to address avoidance

While ACP was seen as a valuable activity, there is avoidance on the part of patients, HCPs and the health care team that needs to be addressed. Both clinicians and patients could be better prepared to have these conversations. In this study, nurse participants reported feeling unprepared, “I don’t ever really remember being taught how to [talk to patients about ACP],” (nurse F6), and rely on, “Experience, you just kind of feel it out,” (nurse F4), or simply refer to a social worker, “I do want to, but I just feel like the social workers are more equipped to handle those situations,” (nurse M2). Patients emphasized the need for interprofessional training and education that addresses the sensitivity of this topic for patients.

Patients and HCPs are also in need of support and information to close communication gaps, “they’ve [had strokes], they’re aphasic, and they can’t tell us what they want, and the family member didn’t even know that they were designated as someone’s health care proxy. They have no idea what their family member would want,” (nurse F3).

3.4.2. Lost opportunities are common

Without ACP, patients are at risk of harm from unwanted care and intervention. Often conversations are delayed until there is an obvious decline in the patient’s condition. Asking about ADs on admission presents an opportunity to open a discussion or provide information; however, participants in this study discussed several missed opportunities to a deeper ACP conversation including workflow pressures and workarounds.

Nurses described the process of asking about a task to be completed. One nurse describes the process of admitting patients,

“if people have nothing, I can’t get a green checkbox unless I tell [the EHR] what I did about that...the easiest way out is to say I gave them the packet...Once I get that green check, I kind of move on to the next thing,”

(nurse M2)

There is little time during the process of admission to follow-up to see if additional resources or information would be helpful, “The follow-up question is definitely important,” (nurse M2), assess whether goals and preferences have changed since the last encounter,

“[EHRs] make it that it’s easy to access information, and a lot of the time, even before the patient comes to the floor, you can literally go into the chart and, oh, I’ll find the scanned copy of the health care proxy. Let me just print it out. And that conversation is already done. So, sometimes it doesn’t even come up because, literally, ‘electronic copy available.’ It’s like, oh, click. We’re golden,”

(nurse M1)

Lastly, nurses expressed time pressures that prevented them from exploring ACP in detail.

4. Discussion

This study explored the challenges and opportunities of implementing ACP processes and educational resources or decision aids in acute care settings. We found that community and acute care patient stakeholders and nurses valued but were challenged by improving the process of ACP in the acute care setting. The focus group data affirmed the complexity of the unique, serious and dynamic ACP process. Each patient situation requires relevant clinical knowledge and judgment as decisions made at one point in time may not be applicable later. ACP is a process that involves the entire team including patients, families, proxies, doctors, nurses, social workers, and chaplains and each has unique responsibilities and contributions to the process.

Our data emphasized the central role of patients in the ACP process to support autonomy and self-determination. Additionally, lost opportunities and avoidance of the ACP process were highlighted. A lack of resources for patients and fragmented documentation processes further confound the process. One of the strongest messages from the nurses and patients in this study was the need to normalize the topic; to ask, reassess and revise ACP whenever possible so that these discussions become a standard part of clinical practice, instead of strictly associated with the impending end of life.

4.1. Strengths and limitations

The strengths of this study include the use of an implementation science framework to organize the findings and the elicitation of both nurse and patient perspectives. The use of an implementation science framework increases the transferability of our findings to other implementation projects because the constructs and subconstructs of NPT are explicit. These strengths increase the applicability of the findings to real-world clinical practice in a way that is meaningful to patients. We consider the results trustworthy, as data saturation was achieved through two nursing and two patient focus groups.

The limitations of this study include a lack of diversity of perspectives from stakeholders. We included nurses and patients; however, perspectives of other members of the interprofessional team such as chaplains, physicians, and social workers would strengthen the findings. Another limitation is three of the four focus groups were situated in a large academic medical center, and practices may vary in other settings. Also, our participants were predominately white, female, and college-educated. Our findings, therefore, may not be transferable to settings outside academic medical centers or among a more diverse population. Lastly, member checking was not completed in this study, and would be recommended in future studies to ensure trustworthiness of the data.

4.2. Implications

The findings suggest that the ACP process requires normalization, clear role delineation, and a more reliable workflow for health care providers. Our findings validate previous research findings (Izumi, 2017; Ke et al., 2015). Nurses need to be educated on their fundamental role in promoting and integrating ACP conversations into clinical practice and in educating and supporting patients in their decision

making. Clinical workflow and EHR requirements need design improvements to support reassessment and documentation of ACP. Incorporating frequent reassessment of ACP needs may help produce the cultural shift towards normalizing ACP conversations. Additionally, access to high-quality educational resources and decision aids will support the nurse's role in educating patients to make informed decisions.

5. Conclusions

ACP is a valuable process and a process in which nurses can be highly active. Our focus groups revealed knowledge gaps and highlighted areas for improvement from nursing and patient participants. Since the passage of the PSDA of 1990, there have not been improvements seen in ACP completion rates. The ACP billing codes introduced in 2016, intended to support the improved implementation of ACP, are underutilized. As we learned through PSDA legislation, without clear implementation support, it is unlikely policy solutions will succeed in improving practice related to ACP. However, approaching ACP with an implementation framework provides an opportunity to embed the process of ACP into practice. The implementation framework of NPT has been successfully used to support intervention development and has framed the analysis of data in this study (May et al., 2018). This use of implementation science will allow findings from this study to be used to develop and test ACP interventions across all health care settings. Establishing a clear ACP process in acute care will require a culture shift and patient engagement. Nurses can play a key role in raising awareness, educating, and improving technical processes.

References

- Aldridge, M. D., & Bradley, E. H. (2017). Epidemiology and patterns of care at the end of life: Rising complexity, shifts in care patterns and sites of death. *Health Affairs*, 36(7), 1175–1183. <https://doi.org/10.1377/hlthaff.2017.0182>.
- American Nurses Association (2010). *Nursing: Scope and standards of practice* (2nd ed.). Silver Spring, Md: American Nurses Association.
- Baker, D. W., Einstadter, D., Husak, S., & Cebul, R. D. (2003). Changes in the Use of Do-not-resuscitate Orders After Implementation of the Patient Self-determination Act. *Berreskuratua* -(e)tik. https://www.ncbi.nlm.nih.gov.ezproxy.lib.umb.edu/pmc/articles/PMC1494855/pdf/jgi_20522.pdf.
- De Vleminck, A., Houttequier, D., Deliens, L., Vander Stichele, R., & Pardon, K. (2016). Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: A phase 0-1 study. *BMC Palliative Care*, 15. <https://doi.org/10.1186/s12904-016-0091-x>.
- Dresser, R. (2016). Medicare and advance planning: The importance of context. *Hastings Center Report*, 46(3), 5–6. <https://doi.org/10.1002/hast.583>.
- Duncan, I., Ahmed, T., Dove, H., & Maxwell, T. L. (2019). Medicare cost at end of life. *American Journal of Hospice and Palliative Medicine*, 1–6. <https://doi.org/10.1177/1049909119836204>.
- Gazarian, P. K., Cronin, J., Dalto, J. L., Baker, K. M., Friel, B. J., Bruce-Baiden, W., & Rodriguez, L. Y. (2019). A systematic evaluation of advance care planning patient educational resources. *Geriatric Nursing*, 40(2), 174–180. <https://doi.org/10.1016/j.gerinurse.2018.09.011>.
- Glick, H. R., Cowart, M. E., & Smith, J. D. (1995). Advance medical directives in U.S. hospitals and nursing homes: The implementation and impact of the patient self-determination act. *Source: Politics and the Life Sciences*, 14(1), 47–59. *Berreskuratua* -(e)tik <http://www.jstor.org/stable/4236097>.
- Hamel, L., Wu, B., & Brodie, M. (2017). Views and Experiences with end-of-life medical care in Japan, Italy, the United States, and Brazil: A cross-country survey. *Berreskuratua* -(e)tik <http://files.kff.org/attachment/Report-Views-and-Experiences-with-End-of-Life-Medical-Care-in-Japan-Italy-the-United-States-and-Brazil>.
- Hospice & Palliative Nurses Association, & Hospice Palliative Nurses Association (2017). *HPNA position statement advance care planning*. (Pittsburgh).
- Hunsaker, A. E., & Mann, A. (2013). An analysis of the patient self-determination act of 1990. *Journal of Human Behavior in the Social Environment*, 23(7), 841–848. <https://doi.org/10.1080/10911359.2013.809287>.
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Institute of Medicine. National Academies of Science. <https://doi.org/10.17226/18748>.
- Izumi, S. (2017). Advance care planning: The nurse's role. *The American Journal of Nursing*, 117(6), 56–61. <https://doi.org/10.1097/01.NAJ.0000520255.65083.35>.
- Ke, L. S., Huang, X., O'Connor, M., & Lee, S. (2015). Nurses' views regarding implementing advance care planning for older people: A systematic review and synthesis of qualitative studies. *Journal of Clinical Nursing*, 24(15–16), 2057–2073. <https://doi.org/10.1111/jocn.12853>.
- Kelley, A. S., Ettner, S. L., Morrison, R. S., Du, Q., Wenger, N. S., & Sarkisian, C. A. (2011). Determinants of medical expenditures in the last 6 months of life. *Annals of Internal Medicine*, 154(4), 235. <https://doi.org/10.7326/0003-4819-154-4-201102150-00004>.
- Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing and Health*, 40(1), 23–42. <https://doi.org/10.1002/nur.21768>.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. *Berreskuratua* -(e)tik Sage Publications https://books.google.com/books/about/Naturalistic_Inquiry.html?id=2oA9aWlNeoc.
- Lund, S., Richardson, A., & May, C. R. (2015). Barriers to advance care planning at the end of life: An explanatory systematic review of implementation studies. *PLoS One*, 10(2), e0116629. <https://doi.org/10.1371/journal.pone.0116629>.
- Marik, P. E. (2015). The cost of inappropriate care at the end of life: Implications for an aging population. *American Journal of Hospice and Palliative Medicine*, 32(7), 703–708. <https://doi.org/10.1177/1049909114537399>.
- May, C. R., Cummings, A., Girling, M., Bracher, M., Mair, F. S., May, C. M., & Finch, T. (2018). Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: A systematic review. *Implementation Science*, 13(1), 80. <https://doi.org/10.1186/s13012-018-0758-1>.
- May, C. R., Finch, T., Ballini, L., MacFarlane, A., Mair, F., Murray, E., & Rapley, T. (2011). Evaluating complex interventions and health technologies using normalization process theory: Development of a simplified approach and web-enabled toolkit. *BMC Health Services Research*, 11(1), 245. <https://doi.org/10.1186/1472-6963-11-245>.
- May, C. R., Rapley, T., Mair, F. S., Treweek, S., Murray, E., Ballini, L., & Finch, T. L. (2015). *Normalization process theory on-line users' manual, toolkit and NoMAD instrument*. *Berreskuratua* -(e)tik. <http://www.normalizationprocess.org>.
- National Center for Chronic Disease Prevention and Health Promotion (2015). *Chronic disease prevention and health promotion*. *Berreskuratua* 2018(e)ko maiatzakaren 1a, -(e)tik <https://www.cdc.gov/chronicdisease/about/multiple-chronic.htm>.
- Nilsen, P. (2015). Making sense of implementation theories, models and frameworks. *Implementation Science*, 10(1), 1–13. <https://doi.org/10.1186/s13012-015-0242-0>.
- Overbeek, A., Korfage, I. J., Jabbarian, L. J., Billekens, P., Hammes, B. J., Polinder, S., & Rietjens, J. A. C. (2018). Advance care planning in frail older adults: A cluster randomized controlled trial. *Journal of the American Geriatrics Society*, 66(6), 1089–1095. <https://doi.org/10.1111/jgs.15333>.
- Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., & Korfage, I. J. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*. [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X).
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity*, 52(4), 1893–1907. <https://doi.org/10.1007/s11335-017-0574-8>.
- Sudore, R. L., Knight, S. J., McMahan, R. D., Feuz, M., Farrell, D., Miao, Y., & Barnes, D. E. (2014). A novel website to prepare diverse older adults for decision making and advance care planning: A pilot study. *Journal of Pain and Symptom Management*, 47(4), 674–686. <https://doi.org/10.1016/j.jpainsymman.2013.05.023>.
- US HR4449 (1990). *Patient self determination act of 1990*.
- Van Scoy, L. J., Green, M. J., Reading, J. M., Scott, A. M., Chuang, C. H., & Levi, B. H. (2017). Can playing an end-of-life conversation game motivate people to engage in advance care planning? *American Journal of Hospice and Palliative Medicine*, 34(8), 754–761. <https://doi.org/10.1177/1049909116656353>.
- Wickersham, E., Gowin, M., Deen, M. H., & Nagykaldi, Z. (2019). Improving the adoption of advance directives in primary care practices. *The Journal of the American Board of Family Medicine*, 32(2), 168–179. <https://doi.org/10.3122/jabfm.2019.02.180236>.
- Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs*, 36(7), 1244–1251. <https://doi.org/10.1377/hlthaff.2017.0175>.