



## Research Article

### Advanced Care Planning: Evaluation of a Multi-Site Program

Kathy Manion\* and Neva Crogan

Department of Nursing, Gonzaga University, Washington, USA

#### Abstract

The purpose of this article is to describe the evaluation of a new multi-site advanced care planning program. This program was piloted in four outpatient clinics located in the Pacific Northwest. Advanced care planning encourages the process of ongoing communication to facilitate patients' understanding of their disease process, and discussion of their values, goals, and preferences for future healthcare decisions. This program was modeled after Gunderson Health's Respecting Choices® program, an evidence-based patient centered, family oriented advanced care planning process that has proven success across the world. Trained facilitators assisted patients and their families to explore, reflect, and discuss goals for making future healthcare decisions in alignment with their values, beliefs and understanding of their chronic disease process. Outcome measures found improved patient and family satisfaction, increased documentation of Physician Orders for Life Sustaining Treatment (POLST), and increased perceptions of self-efficacy in nurses trained to lead these conversations.

**Keywords:** Advanced care planning; Advanced directives; Nurse facilitator self-efficacy; Patient/family satisfaction

#### Summary

The Center for Disease Control (CDC, 2019) and the National Institute on Aging (NIA, 2018) recognize the public health opportunity to educate Americans, especially older adults about advanced care planning [1,2]. Advanced Care Planning (ACP) is a process of planning for current and future medical decisions. The advanced care planning process has transitioned from documenting the presence or absence of completed documents, to encouraging ongoing conversations between the patient, their surrogate decision maker and provider. To be effective this process must include reflections on goals,

\*Corresponding author: Kathy Manion, Department of Nursing, Gonzaga University, Washington, USA, Tel: +1 5093136471; E-mail: manionk@gonzaga.edu

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values and beliefs in each person. Even though ACP has more than twenty-five years of legislative support, beginning with the Patient Self-Determination Act of 1991, studies suggest that ACP participation rates are low [3-5].

In 2017 the CDC found that chronic disease affects almost half of all adults living in the United States and accounts for six out of every ten deaths [6]. As chronic disease progresses, the amount of care delivered and associated costs increase dramatically. Medicare payments to beneficiaries are expected to increase to over \$1260 billion by the year 2028 [7]. Much of this spending occurs in the last weeks to months of a person's life. Thus, ACP becomes even more important for those wanting to control healthcare costs by limiting the ordering of un-wanted medications or costly treatments or procedures.

In the Institute of Medicine's 2014 report on Dying in America, a patient-centered, family-oriented approach to care was recognized as a priority when patients near end-of-life [8]. The quality of communication between healthcare clinicians and patients with advanced illness was felt to be poor. On-going conversations are lacking about disease processes, risks and benefits of treatment, overall prognosis and emotional and spiritual concerns. Some healthcare providers find it difficult to discuss the balance between ongoing aggressive treatment and goal directed care that focuses on quality of life as defined by the patient. If this discussion does not transpire then the default mode is to continue aggressive treatment of disease.

Advanced care planning should be an ongoing process that is integrated into the routine care of patients living with chronic disease. ACP conversations help ensure that patients wishes are known and documented, so that care delivered aligns closely with patients goals, values, and beliefs, and avoidance of care that patients would find unacceptable as they near end-of-life. Using nurse facilitators to help patients and families with ACP discussions offers a promising approach.

Respecting Choices® is an evidenced based, internationally recognized ACP program that has been successfully replicated in multiple healthcare settings across the United States, as well as in other countries [9]. Respecting Choices® emphasizes a person-centered, family-oriented process of shared decision making, focused on honoring an individual's goals and values for current and future healthcare decisions [5]. An accountable care organization located in the Pacific Northwest, implemented an ACP program in four outpatient clinics modeled after Gunderson Health's Respecting Choices® program.

The purpose of this article is to describe the evaluation of a new multi-site advanced care planning program. This program was piloted in four targeted outpatient clinics located in the Pacific Northwest.

#### Background

The values and preferences of patients with advanced illness should guide treatment choices. Prior to implementation of the program, only five percent of patients who were admitted to the hospitals associated with this accountable care organization had a documented Advanced Directive. This number was felt to be unacceptable and

not congruent with the mission and vision of the organization. Subsequently, senior leadership reviewed national data and evidence on advanced care planning programs. A decision was reached to pilot this ACP program in four outpatient clinics associated with the organization. Using Respecting Choices® standardized curriculum, two registered nurses from each of the outpatient clinics were trained as Nurse Facilitators for goal centered conversations with patients and families. The target population was all adult clinic patients who agreed to participate in ACP conversations and who were willing to complete a survey. The patients who were invited to participate included those living with a serious and/or life-limiting illness, advanced frailty, terminally ill patients, or frail elders living in long-term care facilities. Also invited to participate were patients, families, designated health care agents, or close friends of the patients.

Volunteer nurse facilitators received four hours of on-line education, and eight hours of classroom time on Last Steps® conversations. Concepts reviewed in the training program included: general interview skills to promote patient-centered discussions, goal-centered conversations, informed decisions around Cardiopulmonary Resuscitation (CPR) and other care decisions such as the Physician Orders of Life Sustaining Treatment (POLST) form, advanced directives and decisional aides that could be used during these conversations.

## Methods

### Design

This article describes a program evaluation that used a retrospective design to measure patient, family and organizational outcomes.

### Outcome measures

The Manager of the Advanced Care Planning program and the investigator developed outcome measures to be evaluated as part of the program evaluation. Agreed upon outcome measures included:

- Patient/family satisfaction with facilitated interviews of this Advanced Care Planning program.
- Advanced Directives and/or Physician Order of Life Sustaining Treatment (POLST) form completion rate.
- Nurse facilitator perceptions of self-efficacy in leading these advanced care planning conversations.

### Procedures

Procedures and human subject protections were reviewed and approved by the Nursing Research Council and Institutional Review Boards associated with this organization. The targeted population included all adult patients who agreed to participate in Last Steps® Advanced Care Planning conversations and complete the anonymous survey during calendar year 2017. Patient participation was voluntary. The program was offered only to adults who were alert, oriented and able to actively participate.

Using Respecting Choices® standardized curriculum, two registered nurses from each of the outpatient clinics were trained as Nurse Facilitators to lead goal-centered conversations with patients and families. Participation was voluntary for the nurses. A total of eight nurses were selected to participate in this program based on their interest in receiving this additional training, willingness to participate in this program and communication skills.

Nurse facilitators received four hours of on-line education, and eight hours of classroom time on Last Steps® conversations. In addition, one to one mentoring was provided by the program manager who is both a registered nurse and certified as an organizational faculty member for Respecting Choices®. Concepts reviewed in the training program included: general interview skills to promote patient-centered discussions, goal-centered conversations, informed decisions around Cardiopulmonary Resuscitation (CPR) and other care decisions such as the Physician Orders of Life Sustaining Treatment (POLST) form, advanced directives and decisional aides that could be used during these conversations.

After receiving a referral from the attending provider, the nurse facilitator scheduled a time for an ACP conversation that was convenient for the patient, spouse, health care surrogate and any other loved ones who wished to participate. The nurse facilitator began the conversation by introducing the new Advanced Care Planning program, describing concepts related to advanced care planning and then exploring the patients and families' goals, values and belief system. Patients were encouraged to verbalize their understanding of the disease process, symptoms, and share how the illness has impacted their life. Families and loved ones were encouraged to ask questions, verbalize their understanding of the disease process and illness trajectory. Following this discussion, the medical provider was asked to join the conversation to further clarify any potential complications of the disease process, risks and benefits of treatment options, and to review and complete the POLST form if the patient and family were ready to do so.

The survey tools used in this program evaluation were previously developed by Respecting Choices® and adapted with their permission. Patients and family members were asked to complete a satisfaction survey immediately following the ACP facilitated conversation in the office or by mailing it back to the clinic. Questions in this survey focused on patient and family member's perception of the discussion, preparedness to make decisions about their future health care, and effectiveness of the Facilitator in meeting their needs for advanced care planning. A total of fifty-nine patients were referred by their provider and agreed to participate in ACP facilitated conversations. While all of the patients who were referred to the program agreed to participate, only twenty (n=20) of the 59 patients completed the satisfaction survey.

In addition, Nurse Facilitators were asked to complete a self-assessment survey immediately following the training session on ACP facilitated conversations and again six months later. Questions in this survey focused on the nurses' perceived self-efficacy in leading ACP conversations, confidence levels, motivation and preparedness to manage their own emotions, fears or concerns when facilitating these conversations. The program manager distributed and collected the surveys and nurse participation was voluntary. Eight registered nurses volunteered and completed Last Steps® conversation training, and six nurses of the eight nurses agreed to complete the self-efficacy questionnaire.

### Data collection

The program manager is a registered nurse who also serves as Manager of the inpatient ACP program and is certified as organizational faculty for Respecting Choices®. The program manager reviewed the medical record of all patients who were referred for ACP

facilitated conversations and collected descriptive data on patient characteristics including age, gender, race/ethnicity and major diagnosis. Patient/family satisfaction surveys were collected after the facilitated interviews. Advanced Directives and/or POLST form completion rate also was tracked by the program manager. Respecting Choices® granted approval to use Respecting Choices ACP Facilitator Self-Assessment survey for purposes of this program evaluation. Pre and post data on facilitator perceptions of self-efficacy, confidence and preparedness in leading ACP conversations were collected in paper format.

After the program manager reviewed the surveys and forms to ensure that all protected healthcare information was removed, the surveys and forms were given to the investigator for review and analysis. All data was entered by the investigator into a password-protected database using Microsoft Excel. The data was analyzed using Excel Mega stat (version 10.4) software.

## Results

### Characteristics of sample

A total of fifty-nine (n=59) patients agreed to participate in the new ACP program. The average age of patient participants was 72.2 (SD 8.87) and ranged between 52-91 years. Of the 59 participants, 50.8% (n=30) were female, 49.2% (n=29) were male and 98.3% were white and non-Hispanic which is representative of this geographical area. The top three primary diagnoses of participating patients included: cardiovascular disease, cancer, and chronic lung disease (Table 1). These findings align closely with the leading causes of death (Table 2) in adults living in the United States as identified by the CDC [6]. At the end of the conversation 91.4% of patients completed a POLST and/or an Advanced Directive form (n=53). The average time required to complete the ACP conversation was sixty-one minutes.

Demographics & Clinical Characteristics	Mean (Sd)
<b>Age</b>	
Range, y	52-91
Mean, y	72.2
Median, y	71
Range, y	52-91 (8.87)
<b>Gender</b>	
Male	29 (49.2)
Female	30 (50.8)
<b>Race/Ethnicity</b>	
White	58 (98.3)
African American	1 (1.7)
<b>Major Diagnosis</b>	
CVD	11 (18.96)
Cancer	8 (13.8)
COPD	7 (12.1)
Alzheimer's	5 (8.6)
Stroke	2 (3.4)
Diabetes	4 (6.9)
Other	22 (36.2)

Table 1: Patient characteristics (n=59).

Leading Causes of Death per CDC	Number of Patients (%) n=59
CVD	11 (19)
Cancer	8 (13.8)
Chronic Lung Disease	7 (12.1)
Alzheimer's	2 (3.4)
Diabetes	5 (8.6)
Other	4 (6.9)
	22 (36.2)

Table 2: Top five leading causes of death.

### Patient satisfaction

Using a five-point Likert scale (1 = not at all, 5 = very much) patients were asked to provide feedback regarding satisfaction with the program (Table 3). Of the 59 participants, twenty completed the patient satisfaction questionnaire. Of those completing the satisfaction questionnaire, all but one strongly agreed that the ACP discussion was helpful, they felt better prepared to make decisions about their future health care, and that the nurse facilitator helped to meet their needs for ACP (Table 3). The differing patient rated questions number one and two as 4 out of 5 with no additional comments.

Variable	Mean Score
1. I feel the discussion was helpful	4.96
2. I feel better prepared to make decisions about my future healthcare	5
3. I feel the nurse facilitator helped meet my needs for advanced care planning	5

Table 3: Patient satisfaction (n=20).

### Family satisfaction

Using the same five-point Likert scale, families and/or loved ones were asked to rate their satisfaction with the program. All responders rated the survey items a five for "very much" satisfied (Table 4).

Variable	Mean Score
1. I feel the discussion was helpful	5
2. I feel better prepared to support my family/loved ones in decisions regarding their future health care	5
3. I feel the nurse facilitator helped meet my needs for advanced care planning	5

Table 4: Family satisfaction (n=20).

### Nurse facilitator self-efficacy

Of the eight participating nurse facilitators trained to lead ACP conversations, six completed both the pre and post self-efficacy questionnaire (Table 5). By the end of the project, nurse facilitators on average felt more motivated to lead ACP conversations, more confident in facilitating discussions, more prepared to facilitate ACP conversations and better prepared to manage their own emotions, fears or concerns when discussing ACP. While there was improvement in all areas, due to the small sample size, statistical significance could not be established.

Item	PreMean	Post Mean	SD
1. I feel motivated to facilitate ACP conversations	9.0	9.5	2.42
2. I feel confident facilitating ACP conversations	6.83	8.0	1.94
3. I feel prepared to facilitate ACP conversations	7.17	8.17	2.36
4. I feel skilled in using general interview techniques	7.17	8.0	1.32
5. I feel prepared to manage my own emotions, fears, or concerns	8.0	9.0	1.41

**Table 5:** Nurse facilitator reports of self-efficacy.

1= not at all, 10= Very Much

To test the relationship between the number of ACP conversations and the degree of confidence facilitating ACP conversations, it was hypothesized that as the number of ACP conversations increased, the degree of confidence in facilitating these conversations would increase well. Regression analysis was used to test this hypothesis (Tables 6 and 7).

Item	r	r <sup>2</sup>	Std. Error	p
Q2. Dependent Variable. Confidence facilitating ACP Conversations	0.512	0.263	1.86	0.0076
Q6. Independent Variable. Number of ACP Conversations				

**Table 6:** Number of ACP Conversations and Confidence Levels.

Results suggest a moderate relationship between the number of ACP conversations and nurse facilitators' confidence level ( $r=0.512$ ). Nurses' confidence levels increased as they gained more experience in leading ACP conversations ( $p=0.0076$ ).

Item	r	r <sup>2</sup>	Std. Error	p
Q2. Dependent Variable. Confidence facilitating ACP conversations	0.956	0.913	0.638	<0.001
Q3. Independent Variable. Preparedness to lead ACP conversations				

**Table 7:** Preparedness to Lead ACP Conversations and Confidence Levels.

In this analysis there was a strong relationship between nurse's feelings of preparedness in leading ACP conversations and the degree of confidence ( $r=0.956$ ); as the preparedness to lead ACP conversations increased, the degree of confidence to facilitate ACP conversations increased as well ( $p<0.001$ ).

## Summary

- As nurses gained more experience in leading ACP conversations their confidence levels increased
- As feelings of preparedness in leading ACP conversations increased, confidence levels increased
- As nurses gained more experience with ACP conversations, their perceptions of confidence and feelings of preparedness in leading ACP conversations increased

## Discussion

Results suggest that using nurses to facilitate ongoing ACP conversations in primary care settings offers much promise. Both patients

and families were satisfied with the process and found the discussions very helpful. As a result, they reported feeling better prepared to make decisions about their present and future healthcare needs. Patients and families reported that the nurse facilitators "were very informative and answered all their questions". The majority of these conversations ( $n=53$ ) also led to documentation of the patients' wishes in writing, using either a POLST form or completion of an advanced directive form. The completed documents were scanned into the electronic health record so that these would be available to providers across the healthcare continuum.

Over thirty-three hundred patients, age sixty-five or older, were seen in the primary care clinics within the ACO in 2017. The total number of referrals made by primary care providers for ACP conversations was low (59 of 3300, or 1.7%). This represented less than two percent of the older adult population from these clinics.

Training of nurse facilitators is an important component to consider when implementing ACP programs. Modeled after the Respecting Choices® program, all nurse facilitators received training from the manager of the ACP program who is a nurse and certified as an Organizational Faculty member for Respecting Choices®. Feedback from the nurse facilitators suggested that their comfort level in approaching these conversations increased as they gained more experience.

Patient preferences regarding present and future healthcare can change over time, especially as disease progresses and functional status declines. Informing and involving patients in decisions about their care is recognized as a standard of good care [9]. Advanced care planning has evolved over time, from a process that focused on whether there was the presence or absence of an advanced directive, to a process that emphasizes ongoing conversation [10].

Nurses are in an ideal position to initiate ACP conversations. They often are the first to recognize when there are changes in a patient's condition and/or a decline in their functional status. Nurses make up the single largest body of healthcare professionals, and as such, are in an ideal position to influence change and acceptance of ACP as a routine part of chronic disease management [11].

Limitations to this program evaluation included a relatively small sample size. While over 3300 patients age 65 or older were seen in these clinics, only 59 patients were referred by primary care providers for ACP conversations. Providers seemed reluctant to refer patients for ACP conversations. While ACP conversations can be time intensive, nurses can cover much of the content. Providers do not need to be in the room for the entire conversation, and the conversation is a billable, reimbursed expense. Increasing providers understanding of the process as well as benefits of ACP conversations could lead to a greater number of referrals.

## Conclusion

The Institute of Medicine's Report on Dying in America recognizes a patient-centered, family-oriented approach to care as patients near end-of-life as a national priority [8]. The quality of communication between healthcare clinicians and patients with advanced illness is often poor. ACP conversations can help to ensure that patients' wishes are known so that care delivered aligns closely with a patient's goals, values and beliefs and is in concordance with their wishes as they near end-of-life. Advanced care planning should be an ongoing process that is integrated into the routine care of patients living with chronic disease.

Utilizing nurse facilitators to help patients and families with ACP offers a promising approach in ensuring that patients' voices are heard.

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