INCORPORATING ADVANCE CARE PLANNING INTO PRIMARY CARE

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ABSTRACT

Catherine Quintana: Incorporating Advance Care Planning into Primary Care
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Advance care planning (ACP) offers patients and providers the opportunity to plan for future health care needs. Primary care is an ideal setting for ACP, due to the close relationship patients have with primary care providers (PCP). However, rates of ACP in primary care are relatively low. The purpose of this Doctor of Nursing Practice (DNP) project was to explore barriers to ACP at UNC Family Medicine (UNCFM), a primary care clinic serving a large and diverse patient population, and collaborate with stakeholders to improve ACP in this practice.

Clinic stakeholders participated in interviews based on the Ottawa Decision Support Framework. Notes from 17 interviews were analyzed for themes. The most frequently cited barrier was lack of knowledge about ACP; therefore, an educational ACP guide was developed and presented to three PCPs in an hour-long didactic session. ACP billing codes were compared before and after the education session to determine whether education increased rates of ACP.

ACP billing increased very slightly from an average of 0 ACP conversations per provider per 30 days pre-intervention to 0.3 ACP conversations per 30 days post-intervention. In conclusion, education did not yield a significant increase in ACP billing. Lack of a clinical workflow for ACP hindered providers’ ability to conduct ACP. Provider education is a first step, but multiple other interventions are needed to increase ACP rates in primary care.
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LIST OF ABBREVIATIONS

ACP: advance care planning
AD: advance directive
AWV: annual wellness visit
CMS: Centers for Medicare and Medicaid Services
CPR: cardiopulmonary resuscitation
DNP: Doctor of Nursing Practice
DNR: do not resuscitate
EHR: electronic health record
EOL: end of life
HCPOA: health care power of attorney
HRS: Health and Retirement Study
IOM: Institute of Medicine (now the National Academy of Medicine)
IP: interprofessional
IRB: institutional review board
MOST: Medical Orders for the Scope of Treatment
PCP: primary care provider
PDSA: Plan Do Study Act
POLST: Physician Orders for Life Sustaining Treatment
RN: registered nurse
SW: social worker
UNC: University of North Carolina
UNCFM: UNC Family Medicine
CHAPTER 1: INTRODUCTION

Background and Significance

End of life (EOL) care is an issue of interest to older adults, their families, their health care providers, and stakeholders in the United States (U.S.) health care system. EOL care in the U.S. does not consistently meet patients’ desire to die with dignity (Auriemma et al., 2017). The 2015 Institute of Medicine (IOM) report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, describes multiple challenges to EOL care. They include a growing geriatric population, a fragmented health care system, time constraints that limit communication with providers, and an unsustainable increase in the cost of care (IOM, 2015). The IOM report (2015) also recognized that shared decision-making and patient/family participation in advance care planning (ACP) present an opportunity to improve EOL care.

A 2017 international Delphi panel offered the following definition of ACP as a process that “enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate” (Rietjens et al., 2017, p. e546). Discussion and documentation of individual goals and desires are vital to ensure that providers can honor them. Effective communication is key to clarifying patients’ goals and values. Billings and Bernacki (2014) emphasize that the ACP process should also include an opportunity to name a surrogate decision-maker or health care power of attorney (HCPOA), and to document preferences in an advance directive (AD).
ACP has multiple benefits that positively impact EOL care. Evidence shows that ACP interventions increase patient-provider discussions about goals of care, promote alignment of EOL care with patient-defined EOL wishes, enhance the quality of EOL care, and increase patient and family satisfaction with care (De Vleminck, Houttekier, Deliens, Vander Stichele, & Pardon, 2016; Green et al., 2015). While ACP can improve the quality of EOL care in multiple settings – such as acute care and long-term care – primary care is often an ideal setting to have ACP conversations. Primary care providers (PCP) have a close relationship with patients and follow them over time, so they are the preferred provider to initiate ACP (De Vleminck et al., 2016).

**Practice Problem and Purpose of the Project**

Despite growing awareness of ACP and its benefits, multiple barriers hinder incorporation of ACP into primary care and rates of ACP are relatively low. In a nationally representative sample of U.S. adults age 18 and up (n=7,946), 67.8% of respondents reported concerns about EOL care but only 26.3% of respondents had completed an advance directive (Rao, Anderson, Lin, & Laux, 2014). Barriers to implementing ACP are multi-faceted and can be found at the patient, provider, and organizational level. The purpose of this Doctor of Nursing Practice (DNP) project is to explore barriers to ACP at UNC Family Medicine (UNCFM), a primary care clinic serving a large and diverse patient population, and collaborate with stakeholders to improve ACP in this practice.
CHAPTER 2: REVIEW OF LITERATURE

End of Life Care

Death is a universal experience, but wishes and preferences for EOL care vary greatly among individuals. While many people express a hope of dying peacefully, without burdening their family or loved ones, the reality is that death most often results from chronic disease that worsens slowly over time (IOM, 2015). Atul Gawande, a surgeon and advocate for high-quality EOL care, reports that our technologically focused health care system has failed to meet EOL needs such as alleviating suffering, being present with family, and not being a burden, at a high cost to society (Gawande, 2014). The wide array of treatment options, which are available due to technological advances in health care, necessitates in-depth discussion between patients, providers, and loved ones about risks and benefits of treatment and overall goals of care.

Overview of ACP

The Patient Self Determination Act of 1990 legislated a patient’s right to make decisions about EOL care, and promoted AD as a way to designate EOL choices (IOM, 2015). Multiple types of AD are available to document choices about EOL care. Legal documents include the living will and HCPOA. Living wills allow patients to indicate general treatment preferences in the event of sudden illness or permanent vegetative state. HCPOA forms name one primary agent and one back-up agent to make decisions on behalf of patients when they lose decisional capacity. In North Carolina, a practical form is available that combines a HCPOA with a living will. It must be witnessed and notarized, but does not require a health care provider’s signature.
Both the HCPOA and living will specify wishes for future care: the treatment preferences take effect in the event of one of the health conditions described in the living will, and the HCPOA becomes the decision-maker only if the patient loses decisional capacity.

Other directives take immediate effect, and require a signature from a health care provider. The longstanding medical order familiar to patients, families, and providers is the Do Not Resuscitate (DNR) order, which is only valid if signed by a health care provider. It addresses cardiopulmonary resuscitation (CPR) but no other EOL treatment options. DNR orders are associated with reduced CPR, reduced number of hospitalizations, and increased use of hospice care; however, these studies were all observational and there is no clear causal relationship between DNR orders and place or type of care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014).

In hopes of stimulating discussion about comprehensive EOL care, another form was developed. The Medical Orders for the Scope of Treatment (MOST) form (also known as Physician Orders for Life-Sustaining Treatment or POLST in some states) includes preferences about level of care, use of antibiotics, and artificial hydration and nutrition, in addition to CPR (Hammes, Rooney, Gundrum, Hickman, & Hager, 2012). It is meant to provide specific instructions about care for patients with advanced illness in any care setting, and should be respected across care settings (Hammes et al., 2012; Hickman, Keever, & Hammes, 2015). As with the DNR, MOST/POLST orders go into effect once a provider signs them.

Providers report satisfaction with POLST as a reliable expression of patient wishes, a useful tool in EOL communication, and a method to prevent unwanted resuscitation and hospitalization that can move across health care settings (Hickman et al., 2015). Hammes et al. (2012) point out that the HCPOA in combination with a MOST form is useful as it names a
decision-maker in the event the patient becomes incapacitated and addresses patient wishes about treatment options most often faced at EOL.

**ACP in Primary Care**

Health care providers should view ACP as a communication process as well as a document-oriented one. Completion of legal documents and a focus on enforcing written instructions often are not patients’ primary concern in EOL care (Johnson, Butow, Kerridge, & Tattersall, 2016). The *Dying in America* report (IOM, 2015) emphasized that ACP is a process with an ultimate goal of “flexible decision-making in the context of the patient’s current medical situation” (p. 149). ACP should be an iterative process, involving multiple patient-provider discussions throughout the trajectory of serious illness (Ahluwalia et al., 2015). Due to the close relationship and continuity patients often have with their PCPs, this is an ideal setting to have ACP conversations (DeVleminck et al., 2016). Yet, the majority of these conversations occur in the hospital during a medical crisis or even on the day of death, rather than in primary care (Billings & Bernacki, 2014).

**Barriers to Implementation of ACP**

Patient barriers, provider barriers, and organizational barriers all contribute to low rates of ACP in primary care.

**Patient barriers.** Patient barriers include lack of awareness and varying levels of readiness to engage in ACP (Fried, Bullock, Iannone, & O’Leary, 2009; Houben, Spruit, Groenen, Wouters, & Janssen, 2014). The HealthStyles Survey of U.S. adults age 18 and older (n=7,946), indicated that the main reason for AD non-completion was lack of awareness about the function of an AD (Rao et al., 2014). Adults often indicate that they have preferences about EOL care, but have varying opinions about how and when to discuss them. ACP is relational,
meaning that relationships between patients, family members, and health care providers strongly
influence willingness to engage in ACP (Johnson et al., 2016). Both patients and providers often
believe that the other will initiate the ACP conversation when the time comes, and do not initiate
the conversation themselves (Brighton & Bristowe, 2016; Enguidanos & Ailshire, 2016).
Limited awareness and varying levels of readiness in the patient population affect rates of ACP.

While the process of communicating and sharing patients’ goals and values is the primary
focus of ACP, many healthcare systems lack an effective way to measure this process
(Ahluwalia et al., 2015). Rates of AD completion have often been used as a surrogate
measurement, though they capture only the documentation portion of ACP. A systematic review
of 150 studies on rates of AD completion published between 2011-2016 (with data collected
from 2000-2015) found that approximately one in three adults in the U.S. has completed any sort
of AD (Yadav et al., 2017). This systematic review included data on 795,909 adults and included
studies of specific patient populations (n=104) and healthy adults (n=46). Through random effect
meta-analysis, Yadav et al. (2017) found an overall completion proportion of 36.7% for any
advance directive, with further analysis showing 29.3% for living wills, 33.4% for HCPOA, and
32.2% for undefined AD.

When comparing specific patient populations to healthy adults, AD completion rates did
not vary significantly: 38.2% for patients vs. 32.7% for healthy adults (p=0.26) (Yadav et al.,
2017). Studies that assessed AD completion through chart review (n=56) found a 32% rate of
completion, while studies that assessed through patient or surrogate recall (n=94) indicated a rate
of 39.5%; this approached but did not reach statistical significance (p=0.05). Patients 65 and
older completed AD at significantly higher rates than younger adults (45.6% vs. 31.6%,
respectively, p<0.001). Patients in hospice or palliative care (59.6%) and in nursing homes
(50.1%) were the most likely to complete AD compared to other patient populations. Interestingly, Yadav et al. (2017) concluded that rates of AD completion did not increase significantly over the years of data collected (2000-2015) despite legislative and research initiatives to promote AD. Clearly, there is a significant opportunity for patient education and engagement in ACP.

Access to care is also a patient barrier to ACP, which does not occur equitably in the U.S. population. Enguidanos and Ailshire (2016), Hammes et al. (2012), Hickman et al. (2015), and Silveira, Wiitala, and Piette (2015) all noted racial disparities in AD completion rates and preferences. Older Caucasian patients are more likely to complete AD and choose comfort measures only, while racial minorities complete AD less frequently and choose more aggressive treatment options when they do. In an analysis of the Health and Retirement Study (HRS; a nationally representative longitudinal study of older adults in the U.S.), 94.4% of decedents who had an AD were white (Enguidanos & Ailshire, 2016). Evidence suggests that these disparities may be rooted in patients’ opportunity to access care and complete AD, not in their willingness to engage in ACP. In a secondary analysis of two randomized controlled trials on AD completion, Hart et al. (2017) demonstrated that demographic characteristics (i.e. race, gender, income) were not consistently associated with rates of AD completion when all participants had equal opportunity to complete AD. Further research into these disparities is needed, and ACP researchers should take them into account when developing interventions.

**Provider barriers.** Provider barriers include lack of time, insufficient communication skills, emotional discomfort with EOL discussions, and concern about depriving patients of hope (Brighton & Bristowe, 2016; Houben et al., 2014). Also, prognostic uncertainty of specific disease processes may complicate the initiation of ACP conversations. In a focus group study of
general practitioners, DeVleminck et al. (2014) found that participants were less familiar with the end stages of heart failure and dementia compared to cancer; they were therefore less likely to identify key moments to initiate ACP discussions in these patient populations. Considering these barriers, provider education is an important component of ACP interventions.

**Organizational barriers.** The major organizational barrier to ACP is lack of systematic clinical workflows and policies to support ACP (Arnett et al., 2017). Lack of standardized ACP documentation, which is particularly important during transitions of care, also limits the efficacy of ACP (Ahluwalia et al., 2015). As a result of these barriers, ACP is not a routine part of primary care.

One previous barrier to ACP was lack of a reimbursement mechanism to recognize the value of the time spent discussing EOL wishes. In 2015, the Centers for Medicare and Medicaid Services (CMS) corrected this problem and altered the fee service to allow providers to bill for ACP conversations with patients. The encounter must occur face-to-face with the patient or patient’s decision-maker and include discussion of AD. The patient does not have to be present if discussion occurs with the decision-maker, and there is no limit to the number of ACP sessions (CMS, 2015). ACP may occur as part of the Medicare annual wellness visit (AWV) or during any other office visit (CMS, 2015). Patients do not have a co-pay for the AWV but a co-pay does apply at other visits. CMS policy does not require completion of AD to bill for the visit and patients may indicate that they desire life-prolonging care on any AD (Terman, 2016). This policy change reflects a growing awareness of the need for ACP and removed an important organizational barrier to incorporating ACP into routine care. Providers and healthcare systems must now learn how to apply CMS guidelines to seek appropriate reimbursement for ACP.
Impact of the Triple Aim on ACP

One way to evaluate the impact of ACP is to use the lens of the triple aim. The triple aim of health care mandates improvement in the experience of care and population health, while reducing the cost of care (Berwick, Nolan, & Whittington, 2008). Evidence shows that ACP can improve the experience of care by aligning treatment with patient goals of care. In a systematic review of ACP interventions, Brinkman-Stoppelenburg et al. (2014) found that AD were associated with reduced hospital care and use of tube feeding, and with increased focus on comfort versus life prolongation. Complex ACP interventions (involving a communication process that may include but is not limited to written AD) resulted in increased compliance with EOL wishes, such as receiving care at home rather than in the hospital, and satisfaction with care (Brinkman-Stoppelenburg et al., 2014). In a systematic review of ACP interventions in the long term care setting, Martin, Hayes, Gregorevic, and Lim (2016) found low to moderate quality evidence that ACP increased consistency of adhering to patient wishes for EOL care and avoiding unwanted treatments and hospitalization. It also improved the chances of dying in the nursing home (out of the hospital).

Houben et al. (2014) performed a meta-analysis of ACP in inpatient and outpatient settings, and determined that ACP interventions increase AD completion and discussion of EOL wishes. In ACP studies, patients in intervention groups completed AD more often than patients in control groups and AD completion correlated with decreased caregiver burden. Houben et al. (2014) emphasized that discussion of AD is part of the ACP conversation, but patients and families must use the broader ACP process to make decisions at point of care. These systematic reviews and meta-analysis suggest that ACP complies with improving the experience of care component of the triple aim.
Another component of the triple aim deals with population health. Health care providers often express concern that ACP may cause patients to feel fearful, anxious, or hopeless, and some patients report distress or fear related to discussing the EOL (Johnson et al., 2016). However, fear of death is relatively common in the death-avoidant U.S. culture, and discussing ACP does not worsen this already-existing discomfort. Houben et al.’s (2014) meta-analysis found no evidence that ACP creates psychosocial distress such as depression or anxiety in patients. Green et al. (2015) also found that engaging in ACP did not deprive patients of hope or increase anxiety. In fact, ACP discussions that address EOL preferences correlate with higher patient satisfaction with provider communication and higher family satisfaction with the quality of end of life care (Green et al., 2015). These analyses suggest that discussing and planning for EOL may improve population health by aligning treatment with goals of care and enhancing patient-provider communication.

While the primary aim of ACP is to improve the patient/family experience of care, ACP interventions often comply with another component of the triple aim by reducing health care spending. As value-based care provisions (basing reimbursement on the quality of care) replace the fee-for-service structure, health care systems are increasingly conscious of both cost and quality of care. Aggressive EOL care such as mechanical ventilation and intubation in the intensive care unit is costly and often futile. When patients are offered the option of comfort care versus life prolonging care at EOL, most choose comfort care (IOM, 2015).

Analysis of Medicare decedents (n=3,302) in the HRS demonstrated that AD specifying limits in care were associated with less EOL Medicare spending (-$5,585 per decedent, 95% CI - $10,903 to -$267) in regions with high average levels of EOL Medicare spending (Nicholas, Langa, & Iwashyna, 2011). In a systematic review of the effect of facilitated ACP interventions
on the cost of EOL care, Klingler, der Schmitten, and Marckmann, (2016) analyzed 7 studies (n=12,098) whose settings included the hospital (3 studies in the U.S.), nursing homes (1 study in Canada), and patient homes (3 studies in the U.S.). Of the 7 studies, 6 demonstrated reduced EOL healthcare spending and 1 found no impact on cost (Klingler et al., 2016). Cost savings in both of these analyses were based on measurements of total healthcare spending (inpatient and outpatient care, drugs, nursing home care, and hospice) or Medicare spending. Further cost effectiveness research is needed to strengthen the evidence base for the relationship between ACP and the cost of EOL care. Ethical considerations are important in cost analysis, as the main goal of ACP is to improve the quality of EOL care and concordance between patient wishes and care received. Dixon, Matosevic, and Knapp (2015) recommend a long-term perspective on the cost-effectiveness of ACP, to include the impact on unpaid caregivers, community-based care, and quality of life benefits.

Interventions to Address ACP

The available literature includes multiple studies on ACP, offering insight into how to improve current practice. As with the barriers to ACP, interventions to improve it are found at patient, provider, and organizational levels. Often, multi-level interventions are designed to target patients, providers, and healthcare organizations.

Patient-focused intervention. Given that one of the barriers to ACP is low patient awareness of and willingness to engage in ACP, multiple studies focused on patient/family education and engagement. In a systematic review of 38 studies on shared decision-making tools for patients with serious illness, Austin, Mohottige, Sudore, Smith, and Hanson (2015) found that decision tools increased patient knowledge and preparation for treatment choices. Of the included studies, three were tested in a high-quality randomized controlled trial and are freely
available: a decision aid for feeding options in advanced dementia, a booklet to prepare cancer patients to speak with a palliative care team, and an ACP tool for people with low literacy (Austin et al., 2015). This evidence is limited by small study populations, and limited generalizability to the population as a whole (as many studies were on specific patient populations such as advanced dementia). However, multiple studies provided high-quality evidence, which suggests that educational efforts to engage patients in shared decision-making are effective and thus may improve the quality of EOL communication.

**Provider-focused intervention.** Provider education is an important aspect of improving ACP, as many providers report discomfort with and poor preparation for ACP conversations. Chung, Oczkowski, Hanvey, Mbuagbaw, and You (2016) performed a systematic review and meta-analysis of 20 studies on educational interventions to improve healthcare providers’ communication skills in EOL conversations, and found that communication skills training may enhance self-efficacy, knowledge, and communication scores compared to usual curricula. Instructional design typically included didactic lecture (17 studies), small group discussion (16 studies), and/or role-play with direct observation and feedback (16 studies). A high risk of bias, as well as the questionable surrogacy of self-assessed performance measures for competence, limits the results of these studies. The evidence suggests that provider education may increase the quality of EOL communication, but education alone is not sufficient. Interventions that combine education and organizational change are needed for sustainability in practice.

**Organization-focused intervention.** In addition to patient/family engagement and provider education, healthcare systems must support ACP through policies and practices such as clinical workflows, standardized documentation, and ACP support staff, for it to be a beneficial component of care. A systematic review of 12 studies on implementation of a clinical process for
ACP analyzed the operationalization of structured ACP interventions, and described multiple barriers to ACP integration into clinical workflows (Lund, Richardson, & May, 2015). These barriers included time (most ACP interventions were time-consuming), limited numbers and turnover of trained clinicians capable of executing ACP, and inadequate communication of ACP conversations across healthcare settings (Lund et al., 2015). Lund et al. (2015) recommend a simplified decision-making tool and a structured framework for ACP discussions to promote integration of ACP into clinical workflow.

Multi-level intervention. Many of the ACP interventions discussed in the literature are multi-level, targeting patients, providers, and/or the healthcare organization. The Respecting Choices ACP facilitation program appeared frequently as a multi-level intervention. This program developed standardized ACP conversation guides specific to patient needs (one guide for healthy adults, one for adults with chronic medical conditions, and another for patients nearing death). Trained non-physician facilitators are available throughout the countywide health system in LaCrosse, Wisconsin, to have ACP conversations in collaboration with health care providers (Hammes, Rooney, & Gundrum, 2010). There is a standardized process for ACP documentation in the EHR, allowing all providers in the system to access ACP notes. In this county, of the adults who died in 2007-2008 (n=400), 90% had an AD at time of death and 99.4% of those AD were accessible in the medical record (Hammes et al., 2010).

Detering, Hancock, Reade, and Silvester (2010) reported on a randomized controlled trial of the Respecting Choices ACP intervention. Patients and families in the intervention group received ACP from a trained, non-medical facilitator, while those in the control group received standard care. Patients who received the intervention were more likely to be involved in EOL care, and to have their wishes for EOL care documented and respected (Detering et al., 2010).
Patients and families in the intervention group reported higher satisfaction with care, with multiple comments expressing gratitude for being listened to and included in health care decisions. Families of patients in the intervention group had less depression and anxiety, compared with the control group, and were more satisfied with loved ones’ quality of death (Brinkman-Stoppelenburg et al., 2014). Another benefit of the Respecting Choices intervention was that it categorized ACP discussion based on prognosis and disease trajectory, which helps meet the IOM goal of flexible decision-making based on current health status (Billings & Bernacki, 2014). This program demonstrates the potential of a comprehensive ACP process when integrated into a healthcare system; however, it is proprietary and requires significant financial investment to implement.

**Special Considerations in ACP Interventions**

**Timing and prognosis.** Timing ACP conversations strategically throughout a disease trajectory – so that patients and families make decisions relevant to the patient’s current health condition as the IOM (2015) recommends – is essential to maximize the benefits of ACP. Billings and Bernacki (2014) identify this as the “Goldilocks phenomenon:” ACP conversations that occur too early or too late do not provide as much benefit to patients and families as those that occur just in time. Initiating ACP conversations in the hospital is not ideal because patients and families are in crisis, and clinicians are focused on the acute medical needs. These discussions tend to be brief and rushed. Discussing ACP too early is not ideal either: patients often feel differently when they are living with a serious illness, and their choices change as the disease progresses (Billings & Bernacki, 2014).

Providers should use prognostic stratification tools to target patients at an appropriate moment in the disease trajectory (Billings & Bernacki, 2014). Tools specific to one disease
process, such as the Seattle Heart Failure model, are inadequate for patients with complex co-morbidities. Tools that allow for multiple co-morbidities and include functional status are preferred, as functional status is a reliable predictor of mortality (Billings & Bernacki, 2014). Even when providers use appropriate prognostication tools along with their clinical judgment, timing ACP conversations will be difficult.

Given the difficulty of timing of ACP conversations, current evidence recommends that multiple ACP conversations take place. The National Institute on Aging (2016) recommends the following times: once a decade, at the time of a new diagnosis, deterioration or change in health status, change in marital status, and death of a spouse or loved one. Ahluwalia et al. (2015) also emphasize that ACP should be an iterative process that evolves over time, not a discrete task. However, this iterative process would require a significant change in practice, and increased support for the providers initiating ACP conversations. PCPs who follow patients over time may be the clinicians best able to offer strategically timed ACP interventions (Ahluwalia et al., 2015). However, if they are expected to have these discussions then they need organization-level support that recognizes the time and skill required for ACP.

**Documentation.** Effective ACP requires adequate documentation of patient goals and treatment choices that reaches across the continuum of care, from the PCP office to the emergency department. PCPs may have in-depth knowledge of patient values but current electronic health records (EHR) do not communicate those values in a way that could guide decision-making for another provider (Ahluwalia et al., 2015). Standardized ACP templates and alerts to re-evaluate ACP after an acute event could be developed in the EHR to facilitate communication across the continuum of care (Ahluwalia et al., 2015). Ideally, interventions to
improve ACP would implement a standardized documentation process to share patients’ goals and treatment choices with healthcare teams in multiple care settings.

Despite the barriers to ACP, the opportunity to change practice exists and would enhance the quality of care. A systematic approach is needed to address challenges to ACP in primary care. Therefore, the purpose of this DNP project was to conduct a needs assessment to identify barriers to ACP implementation at UNCFM. Following analysis of the needs assessment, stakeholders designed an intervention focused on increasing patient awareness of the need for ACP, improving provider comfort level with ACP, and developing a systematic process for implementation of ACP in the primary care setting.
Kotter’s Change Model

Kotter’s change model provides a conceptual framework to develop an effective practice change for ACP at UNCFM. Kotter’s change model outlines eight steps to accelerate organizational change. Kotter published this model in his 1996 book, Leading Change, and later revised some of the steps in his 2014 book, Accelerate (Burden, 2016; Kotter International, 2017). He developed this change model based on observation of organizations that did not implement change successfully, and created an eight step process to help organizations effect change (Chappell et al., 2016; Kotter International, 2017). This model has been used in several types of organizations, including health care systems, to cope with change (Chappell et al., 2016).

In a 2012 update to his original eight-step process, Kotter highlighted key points about this change model. The steps can be run concurrently, and the focus should be on creation of a network that works flexibly in conjunction with but not within the organization’s hierarchy. Kotter International (2017) published an electronic book that details the eight steps. The eight steps are presented below, with examples of implementation found in the literature.

**Step 1: Create a sense of urgency around a big opportunity that appeals to heads and hearts.** The goal is to engage the workforce in the need for change. Kotter emphasized the need to create an emotional connection to the change, as behavior change is more likely to last if a strong emotion drives it (Campbell, 2008). Organizational leaders should identify, define, and
communicate the opportunity for change. In health care, sharing comparative health data can promote discussion and create the sense of urgency needed. Small et al. (2016) recognized this, and created a sense of urgency by educating staff about the connection between sentinel events and poor communication during nursing handoffs.

**Step 2: Build a guiding coalition of people who can coordinate the larger group of change agents.** This group should connect through opportunity, strategy, and action. The goal is to create a “want to” initiative, not an initiative that people feel that they “have to” undertake (Kotter International, 2017). The coalition should watch for silos or hierarchies that stifle communication and engagement.

**Step 3: Form a strategic vision and initiatives.** The mission statement should have credibility and authority because it came from a diverse group of employees throughout the organization and is endorsed by senior leadership. It should contain common language about goals and priorities. For health care organizations, the vision should not focus solely on cost savings as that is unlikely to motivate health care staff; a service-driven vision statement, such as improving the quality of patient care, may be more inspiring (Campbell, 2008).

**Step 4: Enlist a volunteer army to unite around this opportunity and drive change.** The volunteer army should have members from throughout the organization, avoiding a small group where power is concentrated. Find the people in the organization who are willing to step forward and act. Also, make sure they feel like they have permission to do this and try to remove structural barriers if they do not feel empowered.

**Step 5: Enable action by removing barriers.** Kotter (2012) emphasizes that removing the barriers that keep ideas from becoming reality is key to innovation. Remove ineffective processes, hierarchies, or silos that impede change. What initiatives have already been tried and
why did they fail to become standard practice? The guiding coalition should collaborate with senior management to break down barriers. Pilot testing and continuous evaluation of changes as they are introduced allows for prompt identification of barriers (Casey et al., 2016).

**Step 6: Generate short-term wins.** Collect data that show progress and keep the volunteer army energized. Use (or create) an organizational process for sharing and celebrating achievements. Changes take place over a long period of time, so change agents must show incremental success along the way to maintain engagement. In implementing a new falls prevention workflow, clinic champions encouraged providers to first adopt the workflow with low risk patients and start with one patient per day, which allowed providers to become familiar with the workflow before attempting to use it on complex patients or all patients in their schedule (Casey et al., 2016).

**Step 7: Sustain acceleration by quickly adapting to change.** Remove processes that do not achieve results, and adapt strategically to maintain the change over time. Having clinic champions perform weekly walking rounds of an outpatient clinic was an effective way to promote adaptation to change, as champions were able to help staff adjust to and maintain the practice changes (Casey et al., 2016).

**Step 8: Institute change.** The goal is to sustain change over the long term. Health care researchers who have used Kotter’s model report the difficulty of getting change to stick. Even after successful implementation of an initiative to reduce rates of surgical infection, some staff expressed a desire to go back to old and risky practices even though infection rates had fallen after the intervention (Burden, 2016). Kotter (2012) emphasizes the need to define and share the connection between new behaviors and organizational success. The guiding coalition had to continue to educate staff about the relationship between changing old behaviors and lowering the
infection rate in order to maintain the changes in practice (Burden, 2016). Casey et al. (2016) held ongoing brown bag lunches after implementation of the falls prevention workflow so that staff could share successes and barriers to the new fall prevention workflow, and discuss solutions that improved the workflow in practice. This discussion helped the workflow change become part of the culture.

**Benefits and Limitations of Kotter’s Model**

Though Kotter’s model was not developed for the health care system, health care undergoes constant change and models are needed to adapt to the demands of change (Campbell, 2008; Stoller et al., 2008). Kotter’s model allows for multiple change cycles in a complex change environment, which is beneficial in health care systems (Bradbury, 2014). While Kotter’s model is generally well accepted, it does have limitations. Organizations may find it difficult to implement all eight steps, or may not need each step for every type of change. Chappell et al. (2016) found that some organizations omitted certain steps, or customized the order of the steps, to make effective changes in their practice. Assessment of the model requires time for long-term follow-up. Change typically requires years to take hold and become part of an organization’s culture; therefore, steps seven and eight are particularly time-consuming and complicated to evaluate (Chappell et al., 2016). Kotter’s model does not account for extrinsic forces, such as health policy, that may influence change in health care systems (Noble, Lemer, & Stanton, 2011). Also, it does not provide a prompt for evaluation of project feasibility, which is often a limiting factor. Application of Kotter’s model should remain flexible to adapt to other forces at play in health care systems.

Kotter’s model is intuitive, easy to understand, and based on real-life experience, which likely accounts for its popularity (Appelbaum, Habashy, Malo, & Shafiq, 2012). In fact, one
group of nurses chose Kotter’s model as a framework to implement a practice change because it was clear, easy to implement, and used easy-to-understand imagery (Small et al., 2016). Similarly, Burden (2016) found that the clear vision and focus on consistency facilitated use of Kotter’s model. Overall, Burden (2016), Casey et al. (2016), and Small et al. (2016) found that Kotter’s model provided an effective structure for practice change in health care.

**Application of Kotter’s Model to the DNP Project Plan**

Given the effectiveness of Kotter’s model in other health care quality improvement initiatives, it is used in this DNP project as a framework to guide change in ACP practices at UNCFM. It allows for flexibility in change management, which is important for a large organization like UNCFM. Kotter’s model has been effective in interprofessional teamwork (Small et al., 2016). As ACP ideally is an interprofessional process, the use of Kotter’s model is appropriate for this DNP project (Ho, Jameson, & Pavlish, 2016).
CHAPTER 4: METHODOLOGY

Project Design

The project’s design was guided by a complex needs assessment conducted by graduate students from multiple health professions. This completed step one of Kotter’s model, as the process of the needs assessment built a sense of urgency to improve ACP at UNCFM. Following the needs assessment, the data were presented to key stakeholders at UNCFM in order to identify the best intervention to address the aims of this project. Specifically, the aims of the project were to improve provider awareness of the need for ACP, improve provider comfort level with ACP, and develop a systematic process for implementation of ACP in the primary care setting. This was the beginning of step two of Kotter’s model, creating a guiding coalition united through opportunity and strategy. This was designed as a continuous quality improvement project, with recognition that it could change significantly through the quality improvement process and result in something other than what was originally designed. Kotter’s model was an appropriate framework for this methodology because it allows for change throughout the process.

Setting. The practice setting of this DNP project was UNCFM, a large primary care clinic. UNCFM belongs to a collaborative of primary care practices in North Carolina, known as UNC Physicians Network. As part of an academic medical center, its mission is to offer care that is patient and family oriented, community focused, and evidence-based while maintaining medical education programs for its residents, fellows, and physicians (UNC Department of
Family Medicine, n.d.). Since the clinic serves as a medical residency site, all providers were physicians. At the time of the needs assessment, there was no standardized process to initiate or document ACP at UNCFM.

**Preliminary work.** A team of seven interprofessional (IP) graduate students from nursing (n = 2), medicine (n = 1), public health (n = 3), and social work (n = 1) completed a complex needs assessment of ACP. The IP team, which included one School of Nursing faculty member, collaborated with UNCFM leadership to identify stakeholders and complete the needs assessment of the current practice. Working with the UNCFM leadership to identify a practice need increased support for the needs assessment and subsequent intervention. It was important to engage the leadership early to identify an urgent problem and resulting opportunity for change.

**Measures.** The IP team used the Population Needs Assessment workbook, developed by M.J. Jacobsen and A. O’Connor in 1999 and revised in 2006, to complete the needs assessment. This workbook is part of the Ottawa Decision Support Framework, which promotes shared decision-making and aims to improve the decisional process in health care settings (Légaré et al., 2006). Jacobsen and O’Connor (2006) emphasize that a needs assessment is essential to identify problems, establish priorities, and raise awareness of needs and potential interventions.

**Data collection.** As this project is part of a quality improvement methodology, the UNC Institutional Review Board (IRB) determined that the needs assessment was not human subjects research. UNCFM has an internal IRB committee, which reviewed the proposal and determined that it did not warrant further review. Kotter’s model guided the methodology in order to develop an intervention for sustainable change.

Stakeholders throughout the clinic were approached by two members of the IP team and guided through an oral questionnaire adapted from the Population Needs Assessment workbook
Multiple stakeholders were involved in the project; for clarity, those who participated in the interviews are referred to as interviewees. Interviewees (n=17) included the clinic medical director (n=1), attending physicians (n=7), resident physicians (n=2), a medical student (n=1), a licensed clinical social worker (n=1), a medical assistant (n=1), nurse (RN) case managers (n=2), a registration assistant (n=1), and a patient (n=1). IP team members took notes of the responses and shadowed the interviewees in their clinical roles to observe current ACP practice. The notes were placed in a Microsoft Excel document and analyzed for themes. The social work (SW) student was responsible for coding the themes in the spreadsheet. Once this was done, the IP team met and analyzed the themes to identify the root cause of the problem – that is, the reason for a lack of ACP conversations.

**Thematic Analysis of Preliminary Work**

Four main themes emerged from the analysis, with the number of times the theme appeared in parentheses: knowledge (n=122), documentation (n=62), roles (n=50), and time (n=33). One interviewee summed up multiple themes in a few words, emphasizing the need to train “the right people who interact with the right patient at the right time.” Based on this thematic assessment, the team determined that the primary reason for the low rate of ACP was the lack of a standardized ACP process.

The themes include several categories. Knowledge was the broadest theme, encompassing patient and provider education about ACP, planning for ACP, the ACP process, resources needed for ACP, cost/reimbursement, culture, prioritization, training, decision-making, and readiness to engage in difficult conversations. In total, 15 out of the 17 interviewees brought up knowledge about ACP during the needs assessment. One emphasized the need for ACP knowledge: “Providers need to be comfortable with it. I have a routine and residents/students
feel like it will take forever but [we] have to be comfortable describing terms and using a standardized approach.” Other interviewees reported that providers are not well trained to have ACP conversations, which are difficult conversations to have. All interviewees reported that there is currently no standardized approach for ACP discussions, and that ACP conversations vary based on provider knowledge and comfort level. Patient and provider education became part of the intervention as a result of the knowledge deficit that was evident from analysis of the needs assessment.

Documentation was also a significant theme, with 14 of 17 interviewees discussing the barriers to effective ACP documentation. One shared a particularly frustrating incident: “A few weeks ago I saw an elderly man for hospital follow-up. I had clearly documented his preferences in a MOST form and included it in my most recent note. I wish the neurosurgeons had seen that note before they started drilling burr holes in his head.” Coding of the documentation theme was consistent with this incident, indicating that there is difficulty locating ACP documentation in the Epic EHR, difficulty communicating about ACP across care settings (from the outpatient clinic to the emergency department, for example), and difficulty accessing appropriate ACP forms. Consistent documentation would improve the quality of clinical care and reminders in the EHR potentially could identify patients in need of ACP – but the needs assessment indicated that this was not part of current practice at UNCFM.

Though documentation is key to effective ACP, clinic leaders felt that this was not an appropriate clinical intervention at this time. UNCFM was undergoing system-wide Epic EHR changes, and documentation recommendations could be offered but not implemented in this project. However, strategies for maximizing appropriate Epic EHR documentation will be incorporated into the provider education about ACP.
Thematic analysis also showed that ACP roles should be clarified to make ACP more effective and efficient. All interviewees agreed that physicians have a role in ACP conversations, but several acknowledged the need for other clinic staff (SW, RN case managers, and medical assistants) to have a role as well so that the workload is not solely on the physician. The needs assessment indicated that there is no clear delineation of who is responsible for identifying patients in need of ACP or for follow-up after provider-patient conversations. Cultural factors also affect ACP roles. The culture of stigma around death and dying affects willingness to engage in ACP and fulfill the expectations of each individual’s role. This is true for patients, family members, and all clinicians. Clarifying roles and decreasing stigma are necessary parts of any ACP intervention.

Time was the fourth major theme that emerged during analysis. While time is listed often as a barrier in the literature, interviewees brought it up less frequently than the other major themes (n=33). However, two of the physician interviewees who brought up time described it as “the number one barrier to ACP.” Twelve of the 17 interviewees described time as a barrier due to limited appointment time and the need to address acute concerns during appointments. Setting aside an appointment specifically for ACP was recommended, but no providers described this as routine in clinical practice. Patients often have limited time to come in for appointments, and they need to bring family with them for ACP or take time to discuss ACP with family at home. Time and motivation are also necessary to change practice, and must be factored into an ACP intervention. Appendix 2 provides more details of the themes identified from the interviews.

During a meeting to discuss themes from the needs assessment, the IP team also identified concern about the downstream effect of ACP in primary care. While UNCFM interviewees agreed on the need to have ACP conversations in primary care, the results of that
planning significantly impact care in the acute setting (specifically, emergency room visits and hospitalizations). Planning for transitions of care and documenting ACP so that acute care providers can view it is key to achieving the primary long-term benefit of ACP, which is aligning EOL care received with documented patient goals. The IP team acknowledged that while downstream effects are important and should factor into the sustainability plan, the more immediate need is for an effective and efficient ACP process in the outpatient clinic.

Based on the themes from the needs assessment, the intervention was designed to focus first on increasing patient and provider knowledge of ACP through a patient education booklet and a provider ACP guide, and then on implementing a standardized process for ACP. The process included: identifying patients in need of ACP, initiating the conversation between patient and provider, documenting ACP progress, and follow-up with case management (RN or SW) as needed.

**Intervention Planning**

Following thematic analysis of the needs assessment, a meeting with key UNCFM leadership was scheduled to present the identified themes and collaborate on intervention planning. The meeting to plan the ACP intervention included the medical director of UNC Health Alliance (an integrated network of UNC-affiliated primary care practices that focuses on value-based care models and patient-centered medical homes), the UNCFM clinical business operations manager, two population health specialists from UNC Physicians Network (which includes UNCFM and several other UNC practices), an RN case manager, two members of the IP team, and the IP faculty.

In this meeting, attendees agreed that the intervention should include three major components: patient education, provider education, and clinic workflow. During the needs
assessment, it was discovered that additional practices in the UNC Physicians Network were developing patient education materials, and it was determined that these materials should be included in the intervention at UNCFM. In addition to patient education materials, provider education materials were needed. The team lead collaborated with two clinician experts to develop a provider education guide (see Appendix 3) and then scheduled education sessions about ACP. Attendees at the intervention planning meeting determined that the provider guide should include tools to prepare for ACP before the clinic visit, language to initiate ACP discussions in clinic, and basic education about available legal and medical forms (North Carolina Practical Form, MOST, and DNR). Clinic leaders at this meeting (specifically, the director of Health Alliance and the RN case manager) recognized that establishing a workflow for ACP was key to implementing this change, and chose to have the RN case manager in charge of AWV coordinate the ACP workflow.

The target patient population included patients age 65 and up who had Medicare or a Medicare Advantage insurance plan. This offered providers a simple way to identify patients in need of ACP, as Medicare patients are routinely scheduled for an AWV. ACP may be included in the AWV, or patients may return for additional ACP visits as needed. The UNC Health Alliance director, the RN case manager, and the team lead chose the AWV because it is a visit focused on health prevention, and allows time to discuss ACP. During the needs assessment, interviewees reported that visits for acute and chronic health problems do not allow sufficient time for ACP; therefore, these attendees at the planning meeting chose a wellness visit for ACP. The RN case manager in charge of AWV agreed to coordinate the change in workflow because she was able to identify Medicare patients with upcoming AWV appointments, send them
educational materials in advance, and introduce the topic of ACP before the patients met with their provider during the visit.

Attendees at the intervention planning meeting discussed how to choose a target provider population to initiate this practice change, and ultimately decided to begin with a pilot test involving three physicians in the UNCFM clinic who were also interested in improving ACP in primary care. One was an experienced geriatrician with strong ACP skills, one was an experienced primary care provider who wanted to improve ACP skills, and one was the chief resident who wanted to improve ACP education for incoming residents.

The attendees at the planning meeting chose to use the Plan-Do-Study-Act (PDSA) cycle in the intervention. The PDSA approach allowed for rapid change cycles to make small-scale changes in ACP practice and determine which were most effective. PDSA cycles, from the Institute for Health Improvement’s Model for Improvement, test a change by planning it, implementing on a small scale, studying the results, and acting on those results (Langley et al., 2009). Pilot testing and continuous evaluation of change are recommended at this step in Kotter’s model because they allow for prompt identification of barriers (Casey et al., 2016). This intervention phase of the project lasted one month, during which time two education sessions were offered to accommodate the physicians’ clinic schedules.

Data Collection and Measures

The intervention in this DNP project was assessed using a pre-post assessment of ACP billing, to determine whether it had an impact on the number of ACP conversations that providers marked with billing codes. Billing codes for ACP (current procedural terminology or CPT codes 99497 and 99498) were tracked for the three providers participating in the intervention for one month prior to implementation and then one month post-intervention.
Outcomes to measure the proposed intervention included comparison of ACP billing pre- and post-intervention for the three providers, and an assessment of provider satisfaction with the ACP guide and education sessions. Providers were also asked for an informal count of ACP conversations, to compare with ACP billing.

**Data Analysis**

The frequency of billing codes before and after the intervention was compared. Given the small sample size of three physicians in the ACP education pilot, no statistical software was needed. Physicians were also asked for an informal count of ACP conversations they had with patients post-intervention, to compare with use of the billing codes. Qualitative feedback from the three physicians about their satisfaction with the ACP guide was also collected via email sent two weeks after the education sessions. Three questions were asked: what was useful or not useful about the ACP guide; did it apply to clinical practice; and what suggestions do you have for improving the ACP guide? These questions focused on enhancing the ACP guide with the goal of offering it to other providers in this practice.

Once the data were analyzed, the team lead reported the findings to UNCFMC and continued discussion of the sustainability plan. UNCFM now has ownership of the project, allowing for Steps 7 and 8 of Kotter’s model to be achieved.
CHAPTER 5: RESULTS

The ACP intervention included the following steps. First, the process for ACP was developed based on the needs assessment and conversations with stakeholder leadership. Next, an ACP Guide was created to educate providers about ACP deficits described in the needs assessment. Monthly billing statements were reviewed to determine the number of ACP visits that the three providers billed in the month before the intervention. Billing statements were reviewed for one month pre-intervention because two of the three physicians had new positions as of July 2017 (one was new to the practice, and one became the chief resident); therefore, billing review could not be done for a longer period of time before the educational sessions in August 2017. Next, education sessions about how to apply the ACP guide to practice were conducted. Finally, billing statements for the month after the education sessions were reviewed and compared to pre-intervention billing.

Development of the ACP Process

Using feedback from the needs assessment and the intervention planning meeting, the team lead created a process for ACP based on workflow (Figure 1). Clinic leaders at the planning meeting felt it was important to have an evidence-based process that clinicians could learn and implement quickly (i.e. low burden in terms of time/complexity, to promote translation into practice). Given the distinction between future-looking AD (living will, HCPOA) and here and now medical orders (DNR, MOST), the process divided patients into two groups based on the
surprise question. Lakin et al. (2017) used the surprise question in a prospective implementation trial to improve serious illness conversations in primary care, and reported that it was a simple way to identify patients in need of these conversations. This question is straightforward: would you be surprised if the patient died in the next year? If not, that patient is likely to need a MOST form with decisions about CPR, level of care, artificial nutrition, and antibiotic use. If yes, the patient would benefit from a living will to indicate preferences about future health care decisions. In either case, patients should complete (at minimum) the HCPOA section of the North Carolina Practical Form, as all patients benefit from naming and discussing care preferences with a surrogate decision-maker. The MOST and Practical Form were already available at UNCFM, and clinic leaders wanted to use forms that were already familiar to decrease barriers to implementation (such as learning and becoming comfortable with new forms).

Initially the plan was to coordinate with the RN case manager who was in charge of AWV, so that patients coming in for an AWV were identified before the visit and received ACP as part of the AWV (when there is no co-pay for Medicare beneficiaries). Shortly after the planning meeting, the RN case manager left the practice. AWV time slots decreased to one day per week and were then completed by the RN case manager who was also tasked with chronic care management. This RN was asked to participate in the ACP intervention; however, she replied honestly that she did not have the time to take on another project (none of her previous job duties were taken away when AWV were added). Two SWs were also approached about participating in the ACP intervention, as they were licensed clinical SWs that could bill for ACP. They did not have the time to add ACP conversations to their caseload either, because they managed all the care transition visits and had a more-than-full schedule of those. Due to this
change in staffing and redistribution of clinical responsibilities, the team was unable to establish a standardized workflow for ACP in clinic. The team lead worked with the three physicians to offer provider education, but no other team member was able to fill the role of the RN case manager in identifying patients ahead of time and sending patient education materials. Therefore, while developed, the workflow process could not be evaluated.

Figure 1. ACP Process Map

**Creation and Evaluation of Educational Materials**

The guide “Advance Care Planning Basics for Outpatient Clinicians” was developed to address knowledge deficits about ACP identified in the needs assessment (Appendix 3). Stakeholders from the needs assessment identified educational needs in ACP basics such as medical and legal forms, documentation, and billing, as well as discomfort with initiating ACP conversations. The guide addressed these areas by offering resources on prognostication,
language to introduce ACP to patients/families, a description of medical and legal forms, billing guidelines, and an explanation of how to document ACP in the EHR. Two experts in the field provided content validity and suggestions for language to help providers introduce ACP and normalize the discussion with patients and families.

In addition to the guide, a PowerPoint presentation and examples of ACP documents were part of the materials for the education sessions. The PowerPoint included a definition of ACP and its role in primary care, differentiation between legal and medical forms, and tips for billing and documentation. A Practical Form, MOST form, and DNR form were shown to participants to familiarize them with the main medical and legal ACP documents.

**Qualitative Feedback from the Educational Sessions**

Two weeks after the education sessions, the participants were asked via email to provide qualitative feedback on the educational sessions. One physician preferred to give feedback in person rather than over email, which led to an in-person meeting with notes taken on her input. The other two answered via email. All three reported that the guide was useful in clinical practice. One reported feeling hopeful that providing ACP education would help overcome the time barrier, as increased knowledge would make it easier to complete ACP in clinic. Another reported feeling more aware of the need to do ACP after the education session. The physician that was newest to the practice described,

“I liked reviewing some of the nuts-and-bolts of how to get this done in our office, as that is one thing that has definitely been a barrier for me since starting at this practice – the slightly different office policies, logistics of getting forms completed/entered into the EHR, and the minor differences in how this is implemented in [North Carolina] vs. [Virginia] (where I come from) have kept me from feeling that I could confidently and efficiently get this done until now. The handouts were helpful resources to pull out and use during patient care. I thought the session was a great review of the importance of ACP and some techniques and logistics.”
All three participants had suggestions for improvement. These included increasing detail about billing, adding screenshots of the ACP Activity in the Epic EHR, showing a visual of the North Carolina legal decision-making pyramid, and showing exactly where the forms are located in clinic (rather than showing examples in the education session). At this point in implementation, a new ACP Activity feature was available in the Epic EHR and ACP education provided a window to teach providers to use this new feature. These suggestions were incorporated into the materials, which were then presented to UNCFM residents and a group of UNC Physicians Network case managers as part of the next phase in Kotter’s model to sustain change.

**Billing**

Billing codes were requested from the data manager for the three physicians in the pilot group. None of them billed for ACP in the month prior to the education session. In the month after the education session, one physician billed for one ACP visit; the other two did not bill at all. Table 1 shows pre- and post-intervention billing data. When asked for an informal count of ACP conversations one month after the education session, one physician remembered having three conversations but did not bill for at least two of them because they lasted less than 16 minutes, a requirement by CMS. The other two physicians could not recall any ACP conversations for which they did not bill. At the time of writing, billing data through December 2017 had not been analyzed for a 6-month post-intervention count. When asked for an informal count of ACP conversations through the end of the year, the lead physician replied that ACP conversations had not increased.
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**System Change: Communication and Coalition Building**

One significant result of the DNP project not captured in the previous sections is the communication and coalition building that occurred. Working with the IP team of graduate students created connections between students from different disciplines, which led to awareness of another ACP project in an internal medicine practice. Development of the ACP guide resulted in collaboration with a leading palliative care physician, who created an ACP workgroup that has been meeting quarterly since summer 2017. The developers of the patient education materials at UNC Physicians Network joined that workgroup and shared the materials with the group members. One of the other physicians invited to the workgroup is a clinician leader for the Epic EHR, and is working to increase the functionality of the ACP Activity, including the ability to pull meaningful quality data on ACP conversations. The group is now working with system administrators to promote ACP in the outpatient setting as part of an organization-wide post-acute care strategy.
CHAPTER 6: DISCUSSION

ACP Process

Strategies of communication and perseverance helped to build a coalition of ACP partners, but an effective strategy to enhance ACP through an improved clinic workflow was not established. Staff turnover and full workloads did not allow for incorporation of some crucial aspects of ACP, such as identifying patients in need of ACP before their visits, sending out patient education materials before the visit, or creating a process to retrieve completed AD and scan them into the EHR. One of the major lessons learned was that clinic workflow – especially when it involves the addition of new tasks to a workload – does not change easily. This is critical as to impact change, resources must be set aside so that the whole system embraces the intervention. If the whole system supports the intervention, allowing for clear roles and responsibilities to be articulated, it is less likely that the intervention will be dependent on one person, thus increasing the chance for success.

Evaluation of the Educational Sessions

Although the actual number of ACP conversations did not change significantly after the education sessions, the qualitative feedback received from the three participants indicated that the educational materials increased their knowledge and awareness of ACP. The “nuts-and-bolts” education sessions addressed lack of provider knowledge about ACP, which was a major concern from the needs assessment.
The feedback also referenced the need to change clinic workflow. One provider asked for “more tips/advice on how to efficiently incorporate ACP into patients' overall care and a busy clinic schedule, as I think this is my other big barrier to doing this more consistently.” This request demonstrates the need to implement a clinical workflow for ACP, to support effective practice change. Offering education on how to have ACP conversations, document them, and bill for them, was necessary, but relatively ineffective without process change. Lack of process change likely contributed to the billing data, which showed no significant change in ACP practice.

**Billing**

The frequency of ACP billing did not change significantly post-intervention. Multiple reasons may account for this. For one, the ACP conversation must be at least 16 minutes long, occur face-to-face with a patient or their representative, and not be counted as part of another clinic visit. In the qualitative feedback, one physician could recall at least two instances in which she initiated an ACP conversation that did not last longer than 15 minutes. This indicates that billing data is not the most effective method for tracking ACP conversations, as the subject may be introduced but not meet billing requirements. Currently, no other method to track ACP is available from EHR pathways or the routine quality data pulled by the performance improvement team. This is a significant deficit requiring future attention, as relevant and available outcome measures are key to quality improvement projects.

Given the weakness of billing data, the physicians were asked for an informal count of ACP conversations. This did not differ greatly from the billing data, however, which speaks to the need to change clinic workflow in order to incorporate ACP into the standard of care. Since the process of identifying patients before the AWV, sending them educational materials in
advance, and dedicating time in the AWV to ACP did not take place, no meaningful change in
ACP conversations occurred. Losing the RN case manager to staff turnover, and delegating
AWV to the chronic care manager without reducing any of her other tasks, put the onus on
physicians to introduce ACP during clinic visits. This resulted in one of the main barriers
identified in the needs assessment: lack of time in a busy clinic day. Incorporating process
change is an essential next step in sustaining ACP in this practice.

Communication and Coalition Building

Communication was vital to this DNP project because quality improvement work
depends upon a cohesive message of the problem, end goal, intervention strategy, outcome
measures, and sustainability plan. Kotter’s model emphasizes communication as necessary to
accomplish the steps for change. Collaborating with the IP team for the needs assessment, with
various stakeholders at UNCFM for project implementation, and with other clinicians in the
larger ACP workgroup required continual communication of shared goals and how to reach
them. Coalition building is not possible without effective communication.

A DNP-prepared nurse is well suited to this role of communicator and coalition-builder,
as Essential VI: Interprofessional collaboration for improving patient and population health
outcomes is a foundational outcome of DNP education (AACN, 2006). The team lead developed
a process of reaching out to potential stakeholders, sharing the findings of the needs assessment,
explaining the project goals, and emphasizing the importance of ACP in primary care and
throughout the UNC system. She did this with nurses, social workers, physicians, and
administrators from UNCFM, UNC Physicians Network, and the UNC Palliative Care team.
Gradually, this created to a network of people interested in ACP, which led to a palliative care
physician and ACP expert calling the first meeting of the ACP workgroup. Before creation of
this workgroup, these clinicians and administrators were isolated in silos and unaware of ACP efforts outside their practice setting. Creating the workgroup and collaborating to promote a cohesive and effective ACP strategy throughout the organization has been fundamental to learning throughout this DNP project and to understanding how important coalition building is to practice change.

One example of the ACP workgroup’s collaboration to improve practice involves ACP quality data. Billing is an inadequate outcome measure for ACP (as previously described). A new ACP Activity feature became available in the Epic EHR in August 2017 and users across the healthcare system are still learning to use it; therefore, the current documentation process is not standardized. Also, there is no way to pull ACP outcome measures from it at this point in time. This health system is not alone in this. An international Delphi panel released a framework of patient-centered ACP outcomes in 2017, but reliable and valid tools to measure these outcomes (including user-friendly tools that are integrated into EHRs) are lacking (Sudore et al., 2017).

Currently, ACP workgroup leaders are deciding how to maximize the feature with standard documentation templates and creating a pathway to pull data on outcome measures such as number and depth of ACP conversations, identification of a surrogate decision-maker, AD completion, and whether care given was in accordance with patient and family wishes. A project of this scope requires people from multiple settings and disciplines to be successful, and hopefully, collaboration through the workgroup will foster success.

Adaptation: Unanticipated Findings and Strategies Used

As with any project, barriers arose and required adaptation from the original implementation plan. Attempting to identify an ACP partner in the practice after the RN case manager left caused a delay in implementation. However, this allowed ample time to develop the
ACP education guide and correspond with an expert palliative care physician also interested in ACP. This correspondence led to the identification of others also working on ACP in different practice settings, and the creation of the ACP workgroup.

Eventually, with a bit of patience, another ACP partner was found. The team lead reached out to other stakeholders after the RN case manager left, and learned that two physicians had received a two-year grant to improve ACP in the practice. They were just starting to work on the grant, and agreed to combine this DNP project with their efforts. This collaboration is key to the sustainability of changing ACP practices in this clinic, especially in academic clinical settings where turnover may occur often. It was also important to stay true to the DNP project for system change, rather than having the DNP student ‘be the intervention.’ Changing clinic workflow is the next step in the process, and the work will continue after this DNP project is completed.

**Application of Kotter’s Change Model**

Kotter’s Change Model was used to guide implementation of ACP at UNCFM, and was shown to be a useful model to guide practice change. As the project evolved, the model was not used linearly; some of the steps were re-visited over time. Applications of Kotter’s model, along with lessons learned, are described below and give insight into the value of the DNP as a leader in practice change.

UNCFM leadership identified ACP as a process in need of improvement and planned the needs assessment with the IP team. The needs assessment created a sense of urgency among UNCFM clinicians to consider how to improve ACP in their primary care clinic. One lesson learned here was to broaden the scope of the needs assessment. The team focused only on UNCFM, and did not identify other ACP partners until later in the process. Including them
earlier may have resulted in a more comprehensive needs assessment across the UNC Healthcare system.

Another lesson learned was that while a sense of urgency was important, so was feasibility. Though many of the stakeholders who participated in the interviews and the intervention planning meeting felt a sense of urgency about addressing ACP, changing clinic workflow was not feasible due to lack of a dedicated staff member to focus on this change. Turnover occurs frequently in academic healthcare settings, and the team lead failed to plan for this in advance. Putting one person with a specific role at the center of the intervention was, in hindsight, a weakness because she was not immediately replaced. Also, one person to carry out the intervention does not qualify as a “volunteer army.” Sharing responsibility for implementing the intervention among multiple clinic team members would have increased feasibility. Shared interprofessional responsibility will be part of the ACP workflow as UNCFM continues this work.

The team demonstrated some success in removing the barrier of the ACP knowledge deficit and generating short term wins with the provider education sessions. The three physicians shared positive qualitative feedback about the ACP Guide and education session, saying they felt more comfortable with ACP. This was a short-term win: comfort with initiating conversations was an important start to improving ACP. The education session and ACP guide were then adapted for resident education, engaging more clinicians in the ACP initiative.

The final two steps in Kotter’s model, Sustain acceleration by adapting to change and Institute change (steps seven and eight), remain in the hands of the stakeholders at UNCFM. The physicians with the ACP grant plan to change clinical workflow, implement an ACP billing
policy, and gather ACP quality data (other than billing codes) to demonstrate the efficacy of ACP in primary care.

Limitations

Multiple limitations affected this DNP project. Staff turnover limited the ability to change clinic workflow. The focus on provider education and billing data did not assess patient outcomes or satisfaction. Inclusion of patient-reported outcomes should be part of future PDSA cycles as ACP is incorporated into standard care.

Recommendations for Clinical Practice

The lessons learned from this DNP project led to the following recommendations for clinical practice:

• Develop a workflow that supports ACP in clinic (tailored to the individual practice), using interdisciplinary team members to work collaboratively on ACP.

• Educate EHR users to document ACP appropriately, upload AD and label them correctly, and communicate with users in other settings whenever possible so that ACP notes are accessible to other providers.

• Continue to research effective implementation tactics for ACP in primary care, and to develop EHR features that promote and integrate ACP across healthcare settings.

Sustainability

There is ample opportunity for sustainability of this project. The educational ACP guide and accompanying PowerPoint presentation have been used to train 24 UNCFM residents and a group of UNC Physicians Network case managers; these materials were shared with the ACP workgroup and remain available for future training. Also, the ACP workgroup continues to meet to develop and disseminate a coherent ACP strategy throughout the UNC system. The
collaborating physician continues to work on a two-year ACP grant, with buy-in from multiple clinic stakeholders who have been aware of the project since the needs assessment. Sustainability over the long term requires continued communication about ACP processes, successes and failures, and improvements in clinic workflow to facilitate quality ACP conversations in primary care.
APPENDIX 1: INTERVIEW GUIDE FOR STAKEHOLDERS

Team Member:

Date:

Stakeholder Interviewed:

Intro Pitch

I am a member of an interdisciplinary medical professional seminar working to improve the advanced care planning process at the UNCFM...

Basic Questions

• What makes the advanced care planning process difficult?
• What solutions do you suggest?
• What barriers do you see to implementation?
• What do you believe your role is in advanced care planning?

Additional Notes

•

Key Points

•

Action Items

(Adapted from the Population Needs Assessment workbook, developed by M.J. Jacobsen and A. O’Connor in 1999 and revised in 2006).
**APPENDIX 2: EXAMPLES FROM THEMATIC ANALYSIS**

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Documentation</th>
<th>ACP Roles</th>
<th>Time</th>
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<tbody>
<tr>
<td><em>Patient knowledge:</em> in one visit that the IP team shadowed, the patient was unsure whether he had an advance directive or not, and was wary of the legal aspects of ACP</td>
<td><em>Difficulty locating ACP in Epic:</em> How do we communicate the plan somewhere? Even if you communicate well in the visit, it’s a challenge with other providers. Must get ACP into a useful place in Epic.</td>
<td><em>Responsibility for ACP:</em> One stakeholder said ACP couldn’t be one more thing for physicians to do, so other clinicians should be trained to do ACP. Another stakeholder said that this conversation must happen between the provider and the patient.</td>
<td><em>Significance of Time:</em> The #1 barrier to ACP is time.</td>
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<td><em>Provider knowledge:</em> These are life and death conversations. You wouldn’t expect someone to walk into an operating room and perform surgery without training…Communication is a skill.</td>
<td><em>Difficulty communicating across care settings:</em> “There is no [ACP] template for the outpatient setting; the inpatient template is not as relevant.”</td>
<td><em>Role of SW:</em> Need to coordinate with care manager [SW] to introduce and follow-up on ACP conversation</td>
<td><em>Appointment Time:</em> Even for patients who are terminally ill or experiencing worsening chronic illnesses, the discussion of ACP may not be addressed if patients have more pressing concerns for that appointment. Time/length of appointment is an issue here.</td>
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<td><em>Knowledge of ACP Process:</em> No standardized process is in place for care managers to incorporate ACP</td>
<td><em>Difficulty accessing appropriate forms:</em> Providers are unsure of which forms to give to patients; there is no reminder for patients to bring advance directives to their annual wellness visit</td>
<td><em>Cultural factors:</em> Race, religion, culture, and lack of trust in the healthcare system play a role in ACP conversations.</td>
<td><em>Time to Introduce ACP:</em> Can use any upcoming procedure as a good way to introduce the conversation to patients who might not otherwise have a very obvious reason to bring up the discussion.</td>
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<tr>
<td>Knowledge of need for ACP planning: No current standardized process for ACP in clinic; it’s a difficult conversation about difficult decisions; need to confirm a workflow.</td>
<td>Not the focus of this intervention: It’s important that Epic will be changing in July 2017, so we should not focus all our efforts on using the Epic ACP note because it will likely be different in the Epic update.</td>
<td>Role of Patient/Provider Relationship: Being the same age as patient can make it harder; if the physician knows the patient better then comfort to bring it up may be an issue.</td>
<td>Discuss ACP over time: It’s challenging to re-visit the conversation and be up-to-date on what people want as these vary and there isn’t always time to have the ACP conversation at every visit.</td>
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APPENDIX 3: ADVANCE CARE PLANNING BASICS FOR OUTPATIENT CLINICIANS

Preparing for Advance Care Planning (ACP)
- Consider your patient’s health status and prognosis before the conversation.
- Available tools:
  - e-prognosis (http://eprognosis.ucsf.edu/index.php)
  - Good Outcome Following Attempted Resuscitation for likelihood of surviving a code in the hospital (https://www.gofarcalc.com)
  - Surprise Question: Would I be surprised if this patient died in the next year?

How do I talk about ACP with outpatients?
- Open the discussion: “Today we’re going to talk about advance care planning. First, I’d like to hear your thoughts about your health. What is your understanding of your health condition?”
- Define ACP: “Advance care planning is a process by which you and I make sure that your ideas about use of life-sustaining treatments are honored in the future, if you ever face a serious or life-threatening illness. We talk together about who you want to involve in these difficult choices, and what choices you would make in certain illnesses.”
- Key distinction: ACP anticipates future healthcare needs and applies more to the outpatient setting. Goals of care conversations involve decision-making about immediate healthcare needs and apply more to the inpatient setting.
- Normalize planning: “All adults need ACP. It helps your family and your healthcare providers understand your goals and values in case a sudden event happened and you couldn’t make decisions for yourself.”
  - Sudden event like a car crash or unexpected illness
  - Or, tailor the event to the patient, i.e. if your COPD got worse and you went on a breathing machine
- Who to talk with: “It’s important to talk about this with me when you come to clinic, but it’s even more important to talk with your family and your decision-maker about your goals and values.” (Encourage NC Practical Form available on UNCH Intranet and online from NC Medical Society.)
- Why write it down: “You can simply talk about what matters to you. However, it is a good idea to put your choices in writing. You can changes these forms at any time – they belong to you, and only you can make changes to them. We will review them periodically to make sure they still reflect your wishes, and change them as needed.”
- Don’t rush if not ready: “You do not have to make a decision today – take these materials home, talk to your family, and we will talk about this at your next appointment. I’d like to make an appointment specifically to talk about ACP with you, so that you don’t feel rushed and I have plenty of time to hear your thoughts.”
How do I document ACP in the Epic Medical Record?
Document in Epic ACP Activity as an ACP Note – do this every time you have a significant ACP discussion. This Note format will be accessible on the ACP Epic Page, and other clinicians will find it quickly as a result.

- Create a new encounter. Use the .acpnote dot-phrase.
- Use Haiku to upload a completed HCPOA, living will, or MOST into Epic – put it in the ACP note and into Demographics > Advanced Directives.

How do I bill for ACP in the outpatient setting?

- CPT Codes:
  - 99497 (first 30 minutes)
  - 99498 (each additional 30 min)
- Bill for patients with Medicare
- Ask for patient consent (no co-pay at AWV, may have a co-pay at other visits)
- Document who was there (has to be face-to-face) and what you discussed
- Document the time at the end of the ACP note – do not include this time in another progress note.
  - At least 16 minutes spent on ACP
- Completing a legal form is NOT required to bill

How can I help patients document ACP for themselves as HCPOA or living will?

Legal Advance Directive Forms: must be notarized, not a medical order, can be copied NC Practical Form:

- Healthcare Power of Attorney (HCPOA): names a health care decision-maker for the patient who will make decisions only when the patient cannot
- Living Will: records patient’s desire not to receive medical treatment in 3 hypothetical situations (incurable condition, permanent loss of consciousness, advanced dementia/loss of mental function)
- The complete 5 pages make up the document – should be kept together
- OK to complete one part only (ex: HCPOA but not Living Will – cross out the Living Will page but keep it in the document)
- Available through the UNCH Intranet in English and Spanish, and online for free from the NC Medical Society

5 Wishes:

- HCPOA + Living Will
- Long and in-depth form, with personal/spiritual questions as well as medical and legal plans. Not always appropriate for a clinic visit because of length and complexity. May be best for patients who want to structure a family discussion at home and/or write out detailed plans.
- Available online for a nominal fee (agingwithdignity.org).
Portable Medical Order Forms: provider orders; only the original is valid, cannot copy
Medical Orders for the Scope of Treatment or MOST form (bright pink):
  • For patients who have a progressive serious illness or in your clinical judgment need to make decisions about resuscitation, overall level of care, artificial nutrition/hydration, and antibiotic use
  • No expiration date, review annually or with change in condition
Do Not Attempt Resuscitation or DNR/DNAR order (goldenrod):
  • Resuscitation only
  • Use the phrase “attempt resuscitation” to help patients/families manage expectations about CPR
  • May include an expiration date

How do I decide which form to recommend to my patient?
Recommended for everyone: name a decision-maker (HCPOA) – everyone needs one.
  • At minimum, try to establish the healthcare decision-maker verbally even if the patient is not comfortable completing a legal document.
  • Emphasize to the patient that the legal document is CRITICAL when patients wish to name someone who does not fit the NC statutory sequence of spouse, majority of parents and children, or majority of adult siblings (e.g. a married man who wishes his sister rather than his spouse to decide, or an unmarried couple who wish to decide for each other).

When to add the MOST and/or DNR?
  • These portable orders are primarily designed for patients with progressive serious illness and low probability of survival with resuscitation attempts, but can be used based on strong patient preferences.
  • Ask the surprise question: Would you be surprised if this patient died in the next year? If you wouldn’t be surprised if this patient died in the next year, introduce the MOST.
  • If patient chooses DNR on the MOST form, also do a goldenrod – this is what EMS looks for at home.

How do I structure conversations about decision-making in serious illness?
Use the Serious Illness Conversation Guide (Bernacki et al., 2015) for goals of care conversations
  • Use the guide for decision-making as the patient’s illness is progressing.
  • Provide reassurance as goals of care change (from curative/life-prolonging measures to a comfort-based approach, or any major change in condition): “Focusing on comfort is very important to me as your healthcare provider. Our team will do all we can to support you and your family, and to help you be comfortable.”
  • Offer additional resources as needed, such as palliative care or hospice.
REFERENCES


