BREAKING DOWN BARRIERS TO EARLY GOALS OF CARE DISCUSSIONS WITH TERMINALLY ILL CANCER PATIENTS

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ABSTRACT

VICTORIA MARIE POILLUCCI. Breaking Down Barriers to Early Goals-of-Care Discussions with Terminally Ill Cancer Patients (Under the direction of DR. KELLY POWERS)

Opportunities to discuss options for care when faced with a life limiting disease is the right of all patients. Yet, healthcare provider feelings of awkwardness, fear of diminishing hope, and fear of failing to cure can result in missed opportunities to explore what patients really want for end-of-life care. Because these Goals-of-Care Discussions are not occurring, patients often receive unwanted and expensive care. The purpose of this quality improvement project was to evaluate the effect of education on oncology providers' self-efficacy for Goals-of-Care Discussions, and to explore barriers and opportunities to promote completion of earlier Goals-of-Care Discussions. Two white board scribe videos were created to educate providers and for consideration for future use to show patients as an ice breaker to begin these difficult conversations. The sample included 66 Oncologists, Nurse Practitioners, and Physician Assistants from a large academic cancer center in the southeast United States. A Wilcoxon Signed Rank test showed a statistically significant immediate improvement in the oncology provider's self-efficacy after viewing the videos ($p<.001$). Thematic analysis revealed 5 themes: lack of sufficient clinic time, provider comfort level, documentation as key to communication, protocol development, and oncologist versus palliative care (whose job is it?). Education for healthcare providers and tools to help initiate conversations with patients can help improve self-efficacy in conducting Goals-of-Care Discussion. Future research is needed to look at the cost of unwanted care and how developing a comfort level with having discussions surrounding end-of-life can reduce healthcare costs and improve patient centered care.

DEDICATION

To my husband, Joe, for always being my number one fan and for understanding my need for furthering my education, yet again. Thank you for your love and support.

To my secretary, Abigail, for always standing by my side so that I will never walk alone.

And most importantly, to my daughter Ashley Poillucci. From the moment you came into my life everything I do is meant for you. You are my “why” in this world. I love you from the bottom of my heart and I hope this shows you what a strong woman can accomplish with hard work and dedication. Let nothing stand in your way!

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LIST OF ABBREVIATIONS

ICU	Intensive Care Unit
ED	Emergency Department
GOC	Goals-of-Care
NHPCO	National Hospice and Palliative Care Organization
ASCO	American Society of Clinical Oncology
IRB	Institutional Review Board
SPSS	Statistical Package for the Social Sciences
Mets	Metastatic
NCCN	National Comprehensive Cancer Center
DNR	Do Not Resuscitate
IOM	Institute of Medicine
ACP-SE	Advanced Care Planning Self Efficacy Scale

CHAPTER 1: Introduction

There are nearly 600,000 deaths per year associated with a cancer diagnosis. It is because of this that cancer is the second leading cause of death in the United States (Heron, 2019). One of the biggest challenges faced by oncology providers is how best to improve quality of life for patients, which often involves very difficult ethical and clinical decision-making at the end of life. To enhance quality of life, a focus on improving end of life care has become as important as finding curative treatments. Most patients with a life limiting diagnosis (also referred to as terminal diagnosis) express a desire to die at home but despite this, an estimated 10% still die in the intensive care unit (ICU) and 30% still receive chemotherapy (with inherent negative side effects) in the last month of life (Pfeil, 2015). These patients also experience unwanted aggressive care with emergency department (ED) and ICU stays, along with increased healthcare costs and decreased quality of life. It has been shown that cancer patients who die in the hospital experience more pain, anxiety, and stress than those who die at home (Piggott, 2019). Thus, there is a need to improve end of life care for patients with a life limiting illness. Recent research found that in the age of information, the majority of patients and families would rather understand the course of the disease and have time to make decisions and prepare accordingly (Pfeil, 2015).

Attention to identifying where the breakdown occurs between what patients desire for themselves at the end of life and the actual care they are receiving is vital to improving quality of life. According to Piggott (2019), if communication between medical providers and terminally ill patients improved and occurred at an earlier point in time, then patients’ wishes would be understood and documented leading to less provision of futile aggressive care. These conversations are referred to as “Goals-of-Care Discussions,” and nearly two thirds of terminally ill patients die without ever having had these discussions with their providers (Piggott, 2019). When there is high-quality discussion about what is important to patients and their medical providers help them work through challenging treatment choices, decision-making and patient centered care are improved.

Most often patients approaching end of life experience a fragmented delivery of care with high rates of hospitalizations and multiple poorly managed transitions between health care settings. For example, despite the documented benefits of hospice for end-of-life care, referrals to hospice continue to be delayed. About half (49%) of patients die within 14 days of admission to hospice and over 35% die in less than 7 days according to the National Hospice and Palliative Care report in 2014 (Meghani & Hinds, 2015).

If patients are not having an opportunity to discuss their end of life wishes, then there is a risk they could receive care they did not want. A recent descriptive study conducted by Raskin et al. (2014) examined physician documentation of any discussion at all about prognosis or goals of care with patients diagnosed with terminal lung and pancreatic cancer. The sample consisted of 222 patients that were receiving chemotherapy for advanced metastatic cancer with a prognosis of less than one year to live. Sadly, only 4% had any documentation of a care plan in the event of progressive disease and deterioration. Of these patients, only 39% had been given a referral to palliative care (Raskin, 2015). There is a clear need to identify processes for making Goals-of-Care Discussions a standard part of caring for cancer patients.

1.1 Problem Statement

Research shows that aggressive cancer treatments are occurring despite what patients express as their wishes for end of life. This mismatch indicates that Goals-of-Care Discussions between patients and providers are not commonly occurring. Interventions to facilitate these discussions in practice are vital to ensure that both the patient and provider can provide input and are in agreement with the desired plan of care.

Within the DNP project lead's practice site, an outpatient oncology clinic associated with a large academic institution, it has been noted that Goals-of-Care Discussions do not occur early enough, or in some cases do not occur at all. Patients are presenting to the ED never having been told they are terminal or having discussed end of life wishes with their provider. This then leaves hospitalists, who have never met the patient because they provide care solely in the inpatient setting, responsible to discuss end of life and goals of care. Not only is this difficult for the hospitalist providers, but it is difficult for the patient to hear this news from a stranger. Further, this can result in unwanted aggressive care for the patients near death and more overall psychological stress for the patient and family (Pfeil, 2015). Currently, there is no established process for documenting and communicating end of life wishes or to show that these discussions of shared decision making have occurred between patients and their primary oncology providers.

1.2 Purpose of the Project

Given the documented benefits of earlier Goals-of-Care Discussions regarding options at end of life, and the lack of a process for ensuring these conversations occur and are documented at the project site, this project's ultimate goal was to create and evaluate provider education on Goals-of-Care Discussions and to explore provider perceptions of a video tool created to facilitate the discussions. Additionally, provider views about documenting Goals-of-Care Discussions were explored, with findings pivotal to creating a future facility protocol for conducting and documenting Goals-of-Care Discussions for patients with a terminal cancer diagnosis.

A multifaceted approach was needed to achieve this goal. First, a review of the literature was conducted to describe the benefits, to both patients and providers, of reviewing options of care given a terminal diagnosis. The literature review also sought to identify potential barriers to providers, both physicians and advanced practice providers (Nurse Practitioners and Physician Assistants), having these discussions. Next, the literature review was used to create two white board scribe videos. One video was created to educate providers about the benefits of Goals-of-Care Discussions. In addition to educating providers about the literature, this video provided guidance on how to identify which patients are appropriate to have Goals-of-Care Discussions with by introducing the ‘Surprise Question’ and a review of topics such as Advanced Care Planning and the Five Wishes approach to end of life. The second video was created for the patient to learn about options and decision-making at the end of life. It was created to be a video that providers would be able to use with patients to act as an ice breaker to facilitate initiating these discussions. Provider self-efficacy for having Goals-of-Care Discussions was evaluated prior to and following viewing of the videos. The post-test also included open-ended questions to elicit qualitative data from the providers that will be valuable for developing a protocol for implementing and documenting Goals-of-Care Discussions with terminally ill patients at the project site. Responses to qualitative items were analyzed to identify barriers that still existed after the education and views and input on important aspects of a Goals-of-Care Discussions protocol.

1.3 Clinical Question/PICOT

The PICOT question that guided this project was: Does oncology provider (physicians, nurse practitioners, and physician assistants) self-efficacy for having Goals-of-Care Discussions improve after online education and demonstration of a white board scribing video for use to facilitate discussions with patients?

1.4 Project Objectives

The objectives of this project were to:

1) Identify benefits and barriers to Goals-of-Care Discussions between medical oncology providers and terminally ill patients through a review of the literature.

2) Measure baseline provider self-efficacy for Goals-of-Care Discussions with terminally ill patients, as well as their support for a protocol on implementing and documenting these discussions.

3) Create a provider education video to present evidence on Goals-of-Care Discussions (i.e. benefits and risks of not conducting them as it relates to patient quality of care), guidance on identifying which patients are appropriate via the ‘Surprise Question’ approach, and topics such as Advanced Care Planning and the Five Wishes approach to end of life.

4) Create an ice breaker white board scribe video that providers could use to initiate Goals-of-Care Discussions with patients and include the video as part of the provider education.

5) Administer a post-test to measure provider self-efficacy for Goals-of-Care Discussions, as well as open-ended questions to explore provider views and input for use in future development of a site protocol for Goals-of-Care Discussions.

CHAPTER 2: Literature Review

2.1 Introduction

This literature review was conducted using the databases CINAHL, PubMed, Google Scholar, Cochrane Library, and MEDLINE. The inputted key words were: Goals-of-care, end-of-life, advanced care planning, communication, futile care, palliative care, cancer, and terminal. The review revealed 10 distinct concepts which were used to structure presentation of the literature. The themes are: definition of Goals-of-Care Discussions, support from legislation and professional organizations, benefits of Goals-of-Care Discussions, definition of a good death/"Five Wishes", appropriate patient identification using the "Surprise Question," barriers to end of life discussions, communication, cost of aggressive end of life care, and scribing video as a bridge between provider and patient to initiate these difficult talks.

2.2 Definition of Goals-of-Care Discussions

Honest and open communication between a patient and their health care provider is vital, and it becomes more important when a chronic or life limiting disease nears the end. It is at this juncture that a clear understanding and disclosure of information will allow the patient and provider to engage in shared decision making and address all questions and concerns. It is important for this dialogue to be compassionate and supportive with an understanding that clear knowledge of the agreed upon plan can improve the quality of care at the end of life (Kaldjian, 2009). Having Goals-of-Care Discussions involve helping patients make informed decisions regarding use of life sustaining measures, as well as identifying the patient's desire for pain management and type of care they want to receive if they are unable to communicate this for themselves. These conversations can also involve referral to palliative care or hospice and involve education about the role of these two entities. Discussions should also involve education surrounding advanced directives with the patient and their family. If the patient has dementia, for example, discussions regarding futility of care and clinical ethics could also be involved (Kaldjian, 2009). Goals-of-Care Discussions may include treatment options, prognosis, what quality of life would be, what the dying process would be like, patient values, and patient preferences if certain conditions present themselves (Starr, 2019).

According to Lum and Sudore (2016), there are six key concepts that need to be considered when preparing to have end of life discussions. The concepts are: 1) the patient and family's readiness to begin these important discussions 2) identifying a surrogate decision maker (medical power of attorney) 3) assessment of the patient and family's understanding of the disease status and treatment options that have been offered 4) discussion of the values, goals of care, and options for end of life care 5) methods to document patient preferences within the medical record and 6) revisiting the discussions at every status change or hospitalization or noted progression of disease (Lum & Sudore, 2016).

Discussing Goals-of-Care is a skill. It involves some of the same skills that are needed to deliver bad news but should be separated conceptually from talking about prognosis. They require a different framework and often occur after prognosis has already been discussed. These conversations include the individual's values and preferences and can help providers design the treatment choices to meet these preferences and make sure that the care that the patient receives aligns with what is important to them and their family (LeBlanc, 2020).

Goals-of-Care Discussions are often framed around medical decision-making and interventions for treatment of disease. They will include decisions on whether to forgo cardiopulmonary resuscitation or hospitalization or use of chemotherapy, but they should not be limited to these topics. They also should not be limited to strictly end of life; thus, should not focus only on death and dying. These conversations should surround for the patient how they want to *live* and how best health care professionals can support those choices (LeBlanc, 2020). Kaldjian et al. (2009) conducted a structured literature review of 116 articles to identify if there was a consensus of the top documented Goals- of- Care amongst the research. The top six goals identified were: to be cured; to live longer; to improve or maintain function/quality of life/independence; to be comfortable; to achieve life goals (i.e. preparation of death, remain at home, strengthen relationships, accomplish a particular personal goal, spiritual needs); and to provide support for family/caregiver (Kaldjian, 2009).

2.3 Support from Legislation and Professional Organizations

The California's Right to Know End of Life Options Act was enacted in 2009. It states that physicians and advanced practice providers have a legal obligation to provide terminally ill patients with a complete full disclosure of their prognosis and counseling regarding benefits of hospice care. With this full disclosure, it is required that patients understand that they have a right to refuse treatment and a right to continue treatment. If they choose to continue treatment, they must be offered the ability to meet with palliative care so that they will be offered optimal symptom management. If the provider does not feel comfortable or feels unable to have these conversations, they are obligated to refer them to a provider who will (Peereboom et al., 2012).

New York has a Palliative Care Information Act that was enacted in 2011. It requires providers to offer terminally ill patients who are expected to have less than 6 months to live, referrals and information about palliative care and to discuss options of end of life. The aim of this act was to provide patients the opportunity to be informed about end-of-life care options and the ability to make choices that coincide with their wishes and values (Peereboom, 2012).

The American Nurses Association and the American Association of Colleges of Nursing both recognize and mandate that nurses who are caring for patients at the end of life have a responsibility to encourage patients and families to communicate life preferences. Nurses are also responsible for educating patients and families about information surrounding decisions made (Peereboom, 2012). The National Academy of Medicine and the American Society of Clinical Oncology recommend that health care providers initiate Goals-of-Care conversations. They also recommend that palliative care, which most often includes Goals-of-Care Discussions, be part of the standards of oncology care (Starr, 2019). With all of these professional recommendations, the Centers for Medicare and Medicaid Services began reimbursement for advance care planning and Goals-of-Care Discussions on January 1, 2016 (Modes, 2019).

2.4 Benefits of Goals-of-Care Discussions

Goals-of-Care Discussions are associated with less aggressive and less costly treatment at the end of life. They are also associated with a greater use of palliative care and hospice services (SUPPORT Principal Investigators, 1995). It is believed that the reason that these conversations help improve quality of life and result in less aggressive and less costly care at the end of life is because the patients now have better knowledge of choices and an understanding of their disease process. Goals-of-Care Discussions should occur often, not just once, and should begin early in a patient's treatment (Starr, 2019). These early discussions are associated with less resuscitation, ventilation, and death in the ICU. Palliative care referrals can be made early to assist in symptom management as they are intended to do, rather than reserving palliative care only for end-of-life (Peereboom, 2012).

Patients who have an opportunity to have discussions about what their wishes are at the end of life are more likely to receive the type of care that they desire and that they have expressed. When this is done early, patients have the time to become informed about their decisions and to discuss this with family members. Concerns can also be addressed with family members to identify what is important to them (Peereboom, 2012). In addition, when a patient's wishes are met there is often better bereavement adjustment by family members (Peereboom, 2012).

Goals-of-Care Discussions can also have some circumstances that may require certain unique strategies to address them. For example, the patient may identify some conflicts between their goals and have difficulty overcoming them. The priority of goal setting may also change as disease progresses and reality sets in, changing the timeframe set forth. Lastly, there may be a disagreement between the patient and loved ones regarding the decisions made. If discussions occur in a timely manner, it will allow a dialogue to occur that will help bring all to the same consensus (Kildjian, 2009).

There are also benefits of early Goals-of-Care Discussions for providers. Jackson et al. (2008) conducted a qualitative study that looked at oncologists' approaches to end-of-life care and noted a conceptual model relating communication competence to job satisfaction. It was posed that if physicians acquired the skills needed to have successful end of life discussions with patients, they would begin to feel more comfortable in their role as a change agent. This in turn would improve their relationships with patients and lead to better psychosocial care regardless of the outcome medically. Overall, this would then improve job satisfaction and decrease burnout (Jackson, 2008).

In addition to helping the patient come to terms with what their options are, there is also evidence to support that lack of discussion and clarity about the plan of care moving forward can also lead to job dissatisfaction amongst health care providers with associated emotional distress, burnout, increase in attrition, and litigation. Accepting the limits of medicine and overcoming the taboo of death in circumstances where cure is no longer an option, may help providers let go of the feelings of hopelessness and failure to cure and actually be more present with deeper interactions with their patients and families (Carrieri et al, 2020).

2.5 Definition of a "Good Death" and the Concept of "Five Wishes"

The original concept of hospice was developed to alleviate suffering for both patients nearing the end of life and their family members. It has been suggested that approximately three months is needed for patients to adequately utilize hospice services in the manner in which they were intended (Teno, 2007). In the United States, the average length of stay in hospice was 29 days in 1995 and dropped to 26 days in 2005. Astonishingly, it has also been documented that an average of 30% of patients spend 7 days or less in hospice before they die (Teno, 2007). There continues to be a concern about the number of people accessing hospice care late in the course of their illness. The National Hospice and Palliative Care Organization (NHPCO) reports that 53.8% of patients with Medicare received hospice care for 30 days or less in 2018. With that 27.9% were admitted into hospice care for seven days or less. This is only a proportion of people and does not represent the younger population that may actually defer end of life care more than the seniors (Radulovic, 2020). Despite this data, a study by Teno et al. (2007) examined the perceptions of bereaved family members on the timing of referral to hospice and found only 16.2% thought they were referred to hospice too late. They then surveyed the families to evaluate quality of care received by hospice and found that those considered "referred too late" were identified as those with the highest unmet needs and lower satisfaction (Teno, 2007). This discordance identifies a need for more education as to what services can be provided by hospice and how a terminally ill patient's wishes can be identified and documented more readily to produce a timelier referral.

Discussing death is not easy. Often providers are faced with their own mortality and a feeling of failure as providers; but death is inevitable for all of us. Preventing suffering and helping patients and family/caregivers face this time would help to decrease the suffering for all involved. According to Kehl (2006) who examined what would contribute to a "good death," patients described qualities of "being in control, being comfortable, having a sense of closure, having trust in care providers, recognizing the impending death, and leaving a legacy" (Peereboom, 2012, pg. 251).

The method of using "Five Wishes" was developed with input from health care providers and nurses, as well as lawyers. It is a legal document in 40 states that is used to help patients articulate and document end of life concerns and desires. The document can be found at the website for Aging with Dignity. There are five main statements in this document:

1) The Person I Want to Make Care Decisions for Me When I Can't
2) The Kind of Medical Treatment I Want or Don't Want
3) How Comfortable I Want to Be
4) How I Want People to Treat Me
5) What I Want My Loved Ones to Know

Each person that completes this form is asked to cross out statements they don't agree with or would not want their appointed health care agent to perform. There is also space to input free thoughts of their own personal wishes whether they be personal, emotional, or spiritual (Weiner, 2017).

2.6 Appropriate Patient Identification Using the Surprise Question

To help providers identify which patients would be appropriate for a Goals-of-Care Discussion, White (2017) utilized the 'Surprise Question' which entailed asking: "Would you be surprised if this patient died within the next X (usually 6 or 12) months?" A systematic review and meta-analysis by White et al. (2017) confirmed that the accuracy of this question to predict mortality was 75%. Taking this into consideration, along with other measures such as functional status, may improve the ability to identify those patients appropriate for a Goals-of-Care Discussion, a palliative care referral or a referral to hospice (White, 2017). As we have identified the need for early Goals-of-Care Discussions, this tool may be a helpful way to identify those patients that may be facing a life ending disease and could benefit from beginning the discussions as soon as possible.

Outpatient providers have a prime opportunity to have Goals-of-Care Discussions with patients, but inpatient providers are also faced with this at the time of hospitalization if there has been a change in the patient's status that increases the relevance of these conversations. All patients should be involved in advanced care planning but to help providers identify and prioritize which patients need them the most, they should ask themselves the "Surprise Question" (You, 2014). Lastly, with the concept of appropriate timing of the conversations and appropriate candidates to engage in these conversations, a study by Haggerty et al (2004), which included 126 patients with metastatic disease, found that 84% wanted to discuss the options for goals of care when they were first diagnosed (Haggerty, 2004).

It is also important to be sensitive to those patients that just are not ready to hear that they are terminal or that the end of their life is near. Although health care providers can seek to fix everything and set a proposed plan in motion, they must respect the pace that patients wish to take. For these patients, it may be more of a process than just one conversation. It may take multiple meetings and opportunities for questions to be answered before they are ready to discuss preferences. These conversations may include talking to them about concerns they have about someone, such as a loved one, making decisions for them and what that would mean for their quality of life. It is sometimes best to have discussions with patients and the person they have chosen as a substitute decision maker for them in the same room so everyone can be on the same page (You, 2014).

2.7 Barriers to End of Life Discussions

One of the barriers to oncologists initiating end of life and Goals-of-Care Discussions is the awkwardness it presents and the fear of allowing emotion to dictate the conversation. Based on a systematic review performed by Parker et al as early as 2007, previous research has identified definite areas for improvement when it comes to the communication between the doctor and patient regarding prognosis and issues surrounding end of life care (Parker, 2007). Physicians have been shown to often underestimate the emotional resilience of patients and their desire to be a part of the decision-making process (Back et al, 2008). Some of the perceived barriers to having Goals-of-Care Discussions that have been identified by oncologists in the literature include:

- Religious and cultural beliefs
- Patient denial
- Time constraints
- Low health literacy
- Minimal experience by providers
- Poor family/caregiver understanding of the patient’s disease process

- Poor patient functional status
- Lack of supportive practice environment (Schulman-Green, 2018).

Another consistent barrier described by oncology providers in the literature is that of feeling that they do not have the ability to be honest while still maintaining hope. Many equate honesty about a poor prognosis as destroying hope. Interestingly enough, the opposite may be true. When there is continued open communication, it begins to develop healthy coping which in turn generates hope even in the most difficult circumstances. Oncology providers have an opportunity to help patients redefine hope by exploring what is important to them and talking about what can be done to achieve their goals. Although the obvious hope for a cure is of utmost priority, studies have shown that patients often have multiple concepts of hope: “hope for living longer, finding meaning in life, having special time with loved ones, finding spiritual meaning, and having a peaceful death” (Back, 2008).

Another noted barrier that many physicians report is that they will often wait until there are no other curative treatments available before they feel comfortable discussing end of life. When this happens, patients will often continue to agree to therapy despite its potential for high treatment burden for fear of disappointing the provider or believing that their choices are in the best interest of the patient. When the conversations are delayed, it often becomes too late for certain patient preferences to be honored. In one study by Teno et al. (2002), only 41% of seriously ill patients who preferred comfort care felt that the treatment they were receiving was consistent with their wishes (Teno et al, 2002).

Being a good prognosticator is not always a skill that can be mastered. Many physicians will put off having an end-of-life discussion for fear that the accuracy of their estimates of life expectancy may not be true. Most often physicians will overestimate survival and even with much confidence in their decisions, they often have difficulty communicating these estimates. It is noted though that including an educated estimate is important in Goals-of-Care Discussions, if the patient wishes to hear this information, so they may have an understanding of a time frame that will need to be placed on acting about their desired preferences (Keating et al, 2010).

2.8 Communication

Evidence-based research consistently makes recommendations concerning how to initiate conversations with patients diagnosed with a life limiting disease surrounding dying, life expectancy, potential symptoms that are likely to be experienced and the extent to which there should be caregiver or family involvement (Parker, 2007). When there can be dynamic direct communication between providers and patients, there often is improvement in patient satisfaction and patient outcomes, less anxiety, better adherence to treatments and overall improvement in end-of-life care (Granek et al, 2013).

When a Goals-of-Care Discussion can occur without being rushed and with all relevant parties involved, this leads to better overall outcomes for patients. This communication should include asking questions to learn about patient knowledge of their illness, what realistic options are available, and decisions regarding future planning. American Society of Clinical Oncology (ASCO) guidelines are in place surrounding communication for stage IV lung cancer with guidance for clinicians on how to communicate risks and benefits of treatment options including clinical trials, prognosis, spiritual care, and social support (Ferrell et al., 2016).

Patients often have a conflict between wanting to know more yet fearing the news they are about to hear. Most studies have shown that patients who tended to want more information included those that were younger, more educated, and had a strong professed faith. Patient information needs also change as the disease progresses, where those receiving palliative care were found to require less information than those being treated with curative intent. It is therefore important to continually check on the individual's understanding of the current situation and reassessment of goals (Parker, 2007).

In addition to providing facts and opportunities for discussion of the plan, patients also have a need for emotional support. Pollack et al. (2007) looked at the emotional needs of patients at the end of life. The research showed that patients who are able to express their fears and concerns have less anxiety, depression, and better coping strategies. Their research involved audio recordings of physicians with their patients that had advanced terminal disease. With each interaction they looked for opportunities for empathetic responses. Of the 398 conversations, there were 292 opportunities for an empathetic response. Results showed that the oncologists responded empathetically only 22% of the time (Pollack et al., 2007).

Ensuring good communication when caring for terminally ill patients is paramount, no matter the discipline of the provider. Defining one's roles and contributions should be done when working in a patient centered collaborative practice. "Role blurring" can lead to increased risk for conflict and burnout in the workplace (Suter, 2009). These issues should be worked out before entering into a conversation with patients. With role blurring there needs to be a balance between interdependence for the Advanced Practice Provider and their desire for professional autonomy. Each may have different philosophical backgrounds and ethical considerations when it comes to communicating with patients. Validating and respecting each other's backgrounds will lead to a better consensus as to ways to move the collaboration forward (Suter, 2009). A definition of collaboration by Way, Jones, and Busing (2000) is "an interprofessional process of communication and decision making that enables the separate and shared knowledge and skills of care providers to synergistically influence the client/patient care provided" (Suter, 2009, p. 4).

2.9 Cost of Aggressive End of Life Care

The effects of financial toxicity are becoming more widely identified when looking at the whole person living with cancer. One study by Apostol et al. (2015), looked at the high costs of failing to discuss end of life care. The topic of economic effects and insurance coverage for the proposed plan of care was rarely discussed and this led to increased stress for the patient and caregiver, leading to decreased quality of life and increased risk of morbidity and mortality (Apostol et al., 2015). In a study by Cheung et al (2015), patients receiving aggressive, acute care at end-of-life care incurred 43% higher financial debt than those receiving non-aggressive care and this contributes to financial toxicity and burden for family members, as well as negative clinical and quality of life outcomes. A majority of patients with cancer have expressed a desire to discuss the cost of their choices and what out of pocket expenses may be involved. Yet only 20% have reported having the option of having these discussions with their healthcare team (Starr, 2019).

2.10 Scribing Video as a Bridge

To overcome barriers to having Goals-of-Care Discussions, the use of a video may help to break the ice and begin to open up the dialogue between the patient and provider. One type of video is referred to as a White Board Scribing Video. This video starts with a blank white board and uses dark bold images with a voiceover narrating while the images are being drawn. It is very descriptive, informative, and engaging and appeals to both visual and auditory learners. Despite being so thorough, this format delivers information in a simple way to appeal to all literacy levels (Air et al, 2015). A randomized control trial used a video to facilitate end of life discussions for patients with cancer (El-Jawarhi, 2010). Participants, after meeting eligibility requirements, were either randomized to the video group (N=23) or the control group of verbal narrative alone (N=27). The content was the same for both groups. Participants were then asked to select which level of care they would prefer. Of the participants who had the verbal description, 25.9% of participants preferred life-prolonging care, 51.9% basic care, and 22.2% comfort care. In the video arm, no participants preferred life-prolonging care, 4.4% preferred basic care, 91.3% preferred comfort care, and 4.4% were uncertain ($P < .0001$). Those in the video group were found to have more understanding of the subject matter and were more confident in their decisions. In addition, the study noted that the majority of participants (82.6%) were comfortable in watching the video and felt it was helpful. These participants also expressed that they would recommend it to someone else going through what they were going through (El-Jawarhi, 2010).

There are additional studies that promote the use of visual aids to help with the reduction of uncertainty regarding end-of-life advance care planning. You et al. (2014) described three randomized control trials that found that video-based decision aids, when delivered to older adults living in the community or to outpatient cancer center patients helped to clarify patients' care preferences for end of life as compared to verbal description alone (You, 2014). These findings support the use of video to provide patients with information about Goals-of-Care.

2.11 Conceptual/Theoretical Frameworks

With change comes growth and this is vital for progress. For a change to be successful and sustainable, the change agent needs a structured plan to follow during the planning, implementation, and evaluation of the change (Mitchell, 2013). Given that the literature demonstrates many oncology providers do not initiate Goals-of-Care Discussions early on, facilitating this change in practice will take education and raising of awareness before change will be accepted. In Prochaska and DiClemente's Change Theory, there are five phases involved in change: pre-contemplation, contemplation, preparation, action, and maintenance. The pre-contemplation phase is where a majority of oncology providers may exist. It is in this phase that individuals may not recognize that a problem exists and therefore do not see a need for a behavior change. The contemplation phase is where an awareness of the issue is developed, while the preparation phase entails preparing to change one's own current practices (Prochaska, 1986). This project's educational intervention, including the video for patients, aimed to improve providers' awareness, willingness, and preparation to have Goals-of-Care Discussions with their terminally ill patients. The remaining appeal of this theory is the spiral model that will promote action (conducting and documenting the discussions) and then maintenance for behaviors that may relapse after initiation of change has occurred (Kritsonis, 2004).

Albert Bandura's theory of self-efficacy was originally discussed in his Social Cognitive Theory developed in 1977. The theory states that self-efficacy is an individual's belief in their ability to accomplish a task. When someone feels that they are able to perform a task well, then they will approach the behavior freely and often without reservation. When one feels they are incapable of performing a task well or at all, then their behavior becomes more of avoidance than acceptance (Bandura, 1977; Townsend & Scanlon, 2010). Based on this theory, lack of self-efficacy may explain avoidance behaviors of providers in conducting Goal-of-Care Discussions (i.e. providers may avoid these discussions due to fear they may not perform them well). Therefore, this theory supports educating providers on Goals-of-Care Discussions to improve their self-efficacy for having these discussions in an effort to improve implementation in practice.

CHAPTER 3 Methodology

3.1 Project Design

This quality improvement project utilized evidence from the literature and the barriers that oncology providers describe as preventing timely Goals-of-Care Discussions with terminally ill cancer patients to develop an education video to improve providers' self-efficacy for initiating Goals-of-Care Discussions. Using open-ended questions, providers' views and input were also elicited to aid in future creation of a Goals-of-Care Discussions protocol at the project site to help ensure more frequent and timely discussions, accompanied with proper documentation to uphold patient wishes across settings.

3.2 Sample and Recruitment

Although the patients will be the ultimate beneficiaries of improvement in Goals-of-Care Discussions, this project was developed to facilitate practice change through educating oncology physicians and advanced practice providers (Nurse Practitioners and Physician Assistants). The providers were medical oncology providers who provide direct patient care to oncology patients at sites affiliated with Duke University Hospital. Providers from the main hospital campus, the smaller community hospital campus, and their two affiliated cancer clinics were invited to participate. Convenience sampling was utilized. Inclusion criteria were providers (physicians, nurse practitioners, and physician assistants) who care for oncology patients at the two identified hospitals and two Cancer Center clinics, and the providers can work inpatient and/or outpatient. There was no exclusion by disease group (i.e. type of cancer the providers treat). There are approximately 100 physicians and 50 Advanced Practice Providers within the medical oncology division, and these providers were invited to participate. Exclusion criteria were other advanced practice providers such as Clinical Nurse Specialists or those in an administration role who are not directly caring for patients, Registered Nurses, and non-oncology providers.

3.3 Setting

The setting where providers work were the main hospital campus, smaller community hospital campus, and the two affiliated cancer clinics of Duke University Hospital (i.e. inclusion criteria). These sites are located in both Durham and Raleigh, NC. Recruitment occurred via email, and the intervention and all data collection occurred online in the survey platform Qualtrics. This platform allows for data collection, as well as embedding videos.

3.4 Intervention

Based on information gathered through a comprehensive literature review, provider education was developed which included two videos. The videos were developed with the help of Video Wizards production company and each video averaged about 5 minutes in length. After providing the production company with a script of information about what Goals-of-Care Discussions were and the goals of this project, the two videos were developed. Both videos required collaboration with the company to enhance the visual effects and accuracy of the content.

The first video was developed to provide education for the medical oncology providers. It consisted of information on the quality of life and cost benefits of Goals-of-Care Discussions with terminally ill patients, identified barriers, proper selection of patients that would benefit by asking “The Surprise Question”, communication strategies, advanced directives, steps in advanced care planning by using the “Five Wishes” approach, and documentation and billing capabilities of the interaction.

The next component was a white board scribing video that oncology providers could use to present Goals-of-Care Discussions to their terminally ill patients. The video was designed to act as an ice breaker to begin an open dialogue with patients. This video was not distributed to patients as part of this project but was shown to providers to obtain their views on how this may be helpful to them as a conduit of discussions with patients diagnosed with a life limiting illness. The video presented and defined the options available such as further aggressive treatment, palliative care, and hospice. It discussed the importance of articulating their desires and wishes, and specifically reviewed advanced directives and the importance of documenting their wishes in the event they are unable to speak for themselves. The video also was meant to reinforce that patients are in charge of their care and that they will be supported whatever their decisions may be and that they will not be abandoned during any stage of this process.

3.5 Measurement Tools

Surveys were administered in Qualtrics immediately before and after viewing the educational videos. On the pre-test, a 10-item demographic survey obtained information about participant age, gender, race/ethnicity, degree, disease specialty, years in practice, years in oncology, experience with delivering bad news and discussing end of life, opinion on role of palliative care, and what percentage of their practice consists of terminal patients. See Appendix A for the demographic survey items.

Provider self-efficacy was measured on the pre- and post-test using “The Advanced Care Planning Self Efficacy Scale” developed by Dr. Kristen Baughman and Dr. Ruth Ludwick (Baughman et al., 2017). It is an 18-item survey asking, “How confident are you that you can do the following for patients?” Tool items include communicating bad news, determining the level of involvement the patient wants in decision making, describing advanced care directive options, and providing the patient with treatment options. As per the author directions for scoring the scale, there are actually only 17 items used when assessing overall scale scores. Item 18 (Engage patients in advance care planning conversations) is not included in computation of overall scale scores. A 5-point Likert scale format is used, with response options ranging from 1= “Not Confident At All” to 5= “Very Confident”. The tool is validated and has shown a high level of internal consistency with a Cronbach alpha of 0.95 (Baughman et al., 2017). The tool was developed based on Bandura’s theory of self-efficacy. According to Baughman et al. (2017), if a provider does not have high self-efficacy, this will prevent them from conducting these vital conversations with patients. Permission to use the tool was obtained. See Appendix B for a copy of the tool items and Appendix C for permission to use the tool.

Additionally, one item was administered on the pre-test to measure provider support for a protocol on initiating and documenting Goals-of-Care Discussions (see Appendix D for this item). This item asked: Please indicate your level of support for having a protocol on initiating and documenting Goals-of-Care Discussions. Response options were:

○ I do not support this at all. Type in your concerns:
○ I’m not sure if I support this. Type in your concerns:
○ I do support this. Type in any thoughts you want to share:

Finally, 11 open-ended questions were administered as part of the post-test. These open-ended questions were developed to elicit feedback about the education received and to explore provider views and gain input about developing a protocol on Goals-of-Care Discussions. See Appendix E for the open-ended questions.

3.6 Data Collection Methods

Prior to the project implementation, institutional review board (IRB) approval was obtained from both Duke University Health System and the University of North Carolina at Charlotte. After IRB approval, an email was sent by the project clinical expert to all medical oncology providers (physicians and advanced practice providers) within the two hospitals and two clinic sites of the comprehensive cancer center at Duke University main campus and Duke Raleigh Hospital. The email briefly explained the purpose and procedures of the project and included a link to the Qualtrics project site. A reminder email was sent 2 weeks after the opening of the survey. The Qualtrics project site remained open for one month.

After clicking on the link provided in the email, the Qualtrics project opened. A detailed description of the project purpose, procedures, and measures to protect confidentiality was displayed. Participants were asked to click to provide their consent if they wished to participate in the project. Next, the pre-test opened and included the 10-item demographic survey, the 18-item Advanced Care Planning Self Efficacy Scale, and the item to measure support for a Goals-of-Care Discussions protocol. After completing the pre-test, participants viewed the provider education video, which was followed by viewing the patient bridge video. The post-test then opened and included the 18-item question Advanced Care Planning Self Efficacy Scale and the 11 open-ended questions. After completing the post-test, participants were informed their participation in the project was complete and the Qualtrics site closed. See Table 1 for an outline of the project's timeline.

Table 1. Project timeline.

May 2020	Submitted for IRB approval. Developed provider education video.
June 2020	Developed white board scribing video for patients (for provider demonstration only in this project).
July 2020	Developed Qualtrics project site.
August 2020-September 2020	Recruitment emails sent. Reminder email sent after 2 weeks and Qualtrics project site remained open for 1 month.
October 2020	Qualtrics project site closed. Data transferred for analysis.

3.7 Data Analysis

Quantitative data was transferred from Qualtrics to SPSS version 26 for analysis. Demographic items and the pre-test item to measure protocol support were analyzed using descriptive statistics (frequencies, means, etc.). Mean pre- and post-test scores for each of the 18-items of the Advanced Care Planning Self Efficacy Scale were presented. To determine overall self-efficacy, an average of the 17-items was calculated per scale scoring instructions and presented for pre- and post-education. To detect significant changes in item means and the overall mean from pre- to post-test, paired t-tests were planned. However, the data was not normally distributed and significant changes were detected using Wilcoxon Signed Rank Tests, with significance set at $p < 0.05$.

Responses to the open-ended questions were analyzed using thematic analysis. Braun and Clarke's method was used (Braun & Clarke, 2006). Analysis was conducted by the DNP project lead and project chair by first reading and re-reading the data independently to identify codes based on participant responses. The DNP project lead and project chair then met to discuss codes and identify and agree on themes. Presentation of the themes includes supportive participant quotes to enrich understanding.

3.8 Ethical Consideration

IRB approval was obtained at Duke University Health System and at the University of North Carolina at Charlotte. An exemption was received, with the project deemed quality improvement. Participants were informed (via recruitment email and project information displayed in Qualtrics) that their participation in this project was strictly voluntary. The informed consent was provided to participants when they clicked on the Qualtrics site and the DNP project lead's contact information was displayed so participants could ask any questions they may have had. Participants then clicked to indicate they consented to participate. Qualtrics is password protected and it was set to anonymous. Participants did not report any identifying information (such as name, date of birth, etc.) to protect them in the event there is a personal component that contributes to the difficulty in conducting these conversations. All results were presented in aggregate form. Data is stored on a password protected computer and will be destroyed after 3 years.

Chapter 4: Analysis of Impact

4.1 Sample Size and Demographic Information

There was a total of 108 responses; however, not all respondents completed the post-test. A decision was made to include only those responses with 65% or greater completion of data (which equated to finishing the post-test efficacy scale). Therefore, the final sample size was 66 provider participants (completion rate 65%).

The demographic characteristics of the 66 participants are shown in Table 2 . As shown, the majority of respondents (71.2%) were between the ages of 30-49 years old, white (80.3%) and female (78.8%).

Table 2. *Demographic Characteristics of Participants*

	n	%
Age		
20-29	2	3.0
30-39	22	33.3
40-49	25	37.9
50-59	10	15.2
60 or more years	7	10.6
Gender		
Male	14	21.2
Female	52	78.8
Race/Ethnicity		
Hispanic/Latino	2	3.0
Black/African American	3	4.5
Asian/Native Hawaiian/Pacific Islander	5	7.6
White/Caucasian	53	80.3
Other:	3	4.5

The educational background (degree/license) was closely distributed between physicians (24.2%), Nurse Practitioners (42.4%), and Physician Assistants (31.8%). Participants' years of experiences in oncology are shown in Figure 1.

Figure 1. Participants' years of clinical experience.

There were only 3% of respondents with under 4 years of experience. The largest portion of respondents came from Malignant Hematology accounting for the large bone marrow transplant and malignant hematology and cellular therapy department at this institution. There appeared to be a proportionate distribution with the amount of terminally ill patients seen by these providers, however it was discordant to the frequency of Goals-of-Care Discussions that the respondents reported having. It was reported by 63% that they perform Goals-of-Care Discussion either "Often" or "Very Often". Since there is no standard protocol for documentation of these discussions this would be hard to measure other than this self-report measurement obtained. The participants' professional information is shown in Table 3.

Table 3. Professional Information of Participants.

Provider Breakdown

	n	%
Disease Specialty		
Brain	9	13.5
Breast	5	7.6
Thoracic	6	9.1
GI	5	7.6
GU	4	6.1
Malignant Heme	14	21.2
Gyn Oncology	5	7.6
Palliative Care	4	6.1
Other:	14	21.2
Degree/License		
Physician	16	24.2
PA	21	31.8
NP	28	42.4
Other:	1	1.5
Years of Experience in Healthcare		
1-4	2	3.0
5-9	13	19.7
10-14	16	24.2
15-20	14	21.2
21-25	8	12.1
>25	13	19.7
Years of Experience in Oncology		
1-4	10	15.2
5-9	18	27.3
10-14	10	15.2
15-20	13	19.7
21-25	6	9.0
>25	9	13.6
Percent of Terminal Patients		
0-25	18	27.1
26-50	10	15.1
51-75	14	21.1

76-100%	24	34.6
How often do you have GOC Discussions?		
Very often	19	29.2
Often	22	33.8
Sometimes	14	21.5
Rarely	8	12.3
Never	2	3.1
View About Role of Palliative Care with GOC Discussions		
Shared w/ Provider initiating	60	93.8
Shared w/ Palliative Care initiating	4	6.3

4.2 Self-efficacy

As the participants' self-efficacy for participating in Goals-of-Care Discussions was evaluated before the introduction of the two videos and immediately after watching the two videos, item and scale scores were compared. The Wilcoxon Signed Rank Test was chosen for analysis. This is a nonparametric alternative to the t-test and is often used when tests of normality reveal the data is not normally distributed, as was the case in this project.

First, the item means and standard deviations were evaluated and are presented in Table 4. The Advanced Care Planning and Self Efficacy scale was found to be highly reliable with this project’s sample with a Cronbach Alpha of 0.95. Next, the Wilcoxon Signed Rank Test was conducted to evaluate for significant changes for each of the items. As shown in Table 4, there was a statistically significant improvement for 14 of the 17 items that are used in the calculation of the total scale scores. The 3 items that improved but did not reach statistical significance were 1) finding time to have the discussions 2) clarifying the disease and prognosis, 3) responding empathetically. Additionally, item 18 (Engage patients in advance care planning) showed a statistically significant improvement; however, per the author’s scale scoring instructions, this item was not used when calculating total scale scores.

Next, means for the total scale score were calculated. The mean pretest score was 3.99 (SD=.705) and the mean post-test score was 4.32 (SD=.592). Using the Wilcoxon Signed Rank Test, there was a statistically significant improvement in self-efficacy for conducting Goals-of-Care Discussions after watching the white board scribe videos, z = -5.040, p< .001, with a medium to large effect size (r=0.44). This is utilizing the Cohen (1988) rules of gaging effect size (Lakins, 2013).

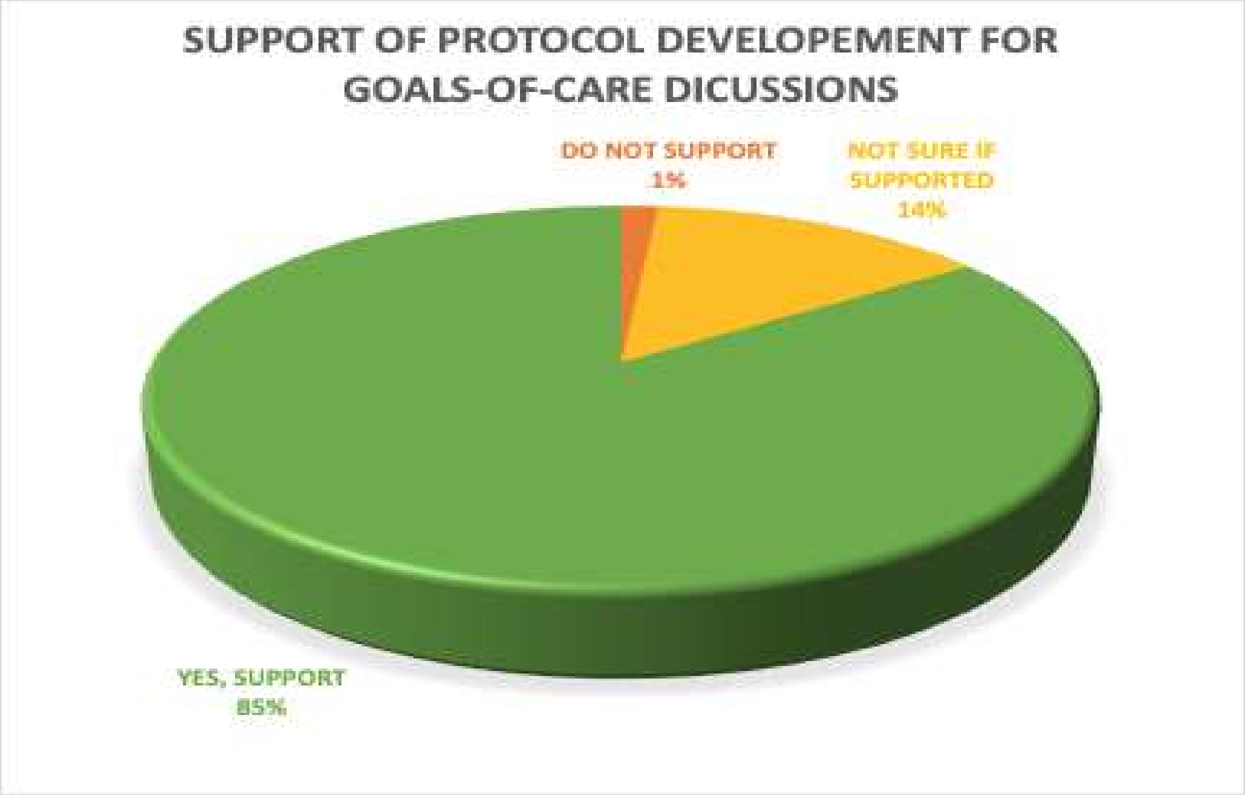
Table 4. *Advanced Care Planning Self-Efficacy Scale*

Item	Pre Mean (SD)	Post Mean(SD)	Change	p-value
1. Find time to discuss	4.02 (1.045)	4.21(0.848)	0.19	0.197
2. How much the patient wants to know	4.08 (0.847)	4.38 (0.690)	0.30	0.001
3. Level of involvement the patient wants	4.02 (0.886)	4.38 (0.718)	0.36	0.001
4. Who else to be involved	4.11 (0.930)	4.44 (0.669)	0.33	0.004
5. Provide the desired level of information	3.82 (1.021)	4.38 (0.690)	0.56	0.000
6. Pros/cons life-sustaining treatments	4.05 (1.029)	4.35 (0.789)	0.30	0.032
7. Specific types of medical treatment	4.03 (0.841)	4.35 (0.688)	0.32	0.009
8. Discuss/negotiate treatment goals/plans	3.95 (0.867)	4.33 (0.760)	0.38	0.000
9. Honor treatment preferences at facility	3.89 (1.111)	4.25 (0.947)	0.36	0.048
10.Honor treatment preferences at hospital	3.56 (1.204)	3.98 (0.980)	0.42	0.020
11. Discuss how to complete living will	3.06 (1.251)	3.52 (1.163)	0.46	0.000
12. Determine when a shift in care goals	4.00 (0.961)	4.33 (0.810)	0.33	0.009
13. Reassess wishes when a shift in care	4.11 (0.862)	4.44 (0.669)	0.33	0.001
14. Openly discuss uncertainty	4.18 (0.910)	4.48 (0.641)	0.62	0.003
15. Clarify disease/prognosis	4.24 (0.842)	4.38 (0.690)	0.14	0.088
16. Respond empathetically	4.55 (0.683)	4.62 (0.599)	0.07	0.405
17. Communicate “bad news”	4.18 (0.910)	4.50 (0.610)	0.32	0.003
18. Engage patients advance care planning	3.95 (1.029)	4.42 (0.723)	0.47	0.004

4.3 Support for Site Protocol

The pre-test also asked participants about their support for developing a protocol surrounding Goals-of-Care Discussions at this institution. Overwhelmingly, as seen by the pie chart in Figure 2, the need for a standardized protocol for conducting Goals-of-Care Conversations was supported at this institution.

Figure 2. Support for protocol at site.



4.4 Qualitative Themes

Thematic analysis was conducted using the Braun and Clarke's method which revealed five main themes: 1) time as a barrier to completion 2) provider comfort level as a barrier that can be addressed with education 3) documentation is vital for communication 4) varied opinions about protocol development and 5) Us vs. them (Braun & Clarke, 2006).

4.4a Time as a barrier to completion

There was noted consistency in participant responses that "*time is the biggest barrier*" and there is a need for dedicated time and space to have Goals-of-Care Discussions. It was felt that if they could have dedicated time, then Goals-of-Care Discussions could be more effective. Responses indicated that having these types of discussions can take time and they should not be rushed because "*if a provider is rushed it is going to be a more challenging discussion*." Further, it was felt that documentation of Goals-of-Care Discussions within the electronic medical record would be yet another source of time consumption: "*Goals of care adds more time onto clinic visits. Adding more documentation and 'clicks' into EPIC also places a burden on the care provider.*"

A suggestion was made for separate Goals-of-Care Discussion appointments so they would not be rushed and could be given the attention needed. One participant explained, "*Time is a big barrier. Could make a separate visit for this discussion or plan during a time of day when you can afford extra time with the patient*." Regarding these separate Goals-of-Care Discussions appointments, a suggestion was made for there to be a support person available such as social worker, grief counseling expert, therapist, etc. within the clinic to meet with the patients and their family/caregivers.

It was also felt that by initiating Goals-of-Care Discussions earlier, they could be briefly re-visited during clinic visits which would be less time-consuming. One participant explained: "*Normalizing a goals of care discussion from early in the disease course (at first metastatic disease, for example) may make it easier to address again as the situation changes*." Another provider put it eloquently by stating, *"Our patients decline rapidly and spend very little time on hospice, making it crucial to initiate conversations early on, instead of one big conversation. I think of it as planting a seed and watering it a little bit at each visit, so it does not feel so overwhelming to patients and families."* It was also felt that use of the patient icebreaker video may enrich patient and family understanding and promote better and faster Goals-of-Care Discussions during clinic visits. One participant stated, "*time constraints for clinic visits [is a barrier]...to overcome we could use the videos to initiate the discussion and proceed with* *discussion over several visits*." Participants described how videos on a tablet, or some portable device would allow the patient to view them in the room prior to their time with the provider. This may help to prompt questions to reach a mutually agreed upon place to start the Goals-of-Care Discussions.

4.4b Provider comfort level is a barrier that can be addressed with education

Having a discussion with a patient that may be facing death is never easy. It is posed that with more education and practice that perhaps clinicians may feel more comfortable in initiating these conversations. One participant wrote: *"This topic is so important and needed in our clinical site/cancer center. Provider education and an available protocol will be very helpful in standardizing these crucial discussions and documenting that they have happened."* Another comment supported education for providers*: "Education is an important aspect and should be included in formal fellowship training and beyond as needed. Learning about newer communication tools/techniques is always helpful." Interestingly there were opposing comments such as, "The provider video is all information that the providers know…they just don't implement it! I am very supportive of the ongoing efforts on GOC...they key is trying to find a way to convert/motivate action on the part of the provider. I think they have heard the data previously."*

Many participants described feeling awkward and uneasy in having these discussions. They described a fear of "*removing hope.*" When asked if they had received training for end-of-life discussions or delivering bad news, most described a didactic approach with course lectures or continuing medical education. Few described mentoring as a method of becoming more comfortable. Of the few that described a high comfort level with having these discussions, they also described their belief that the role of these discussions fell with palliative care and hospice.

This is an interesting finding in that most of the other participants felt it was the primary oncologists' role and not necessarily palliative care alone to conduct these conversations, yet they were the ones who felt most uncomfortable in having Goals-of-Care Discussions.

A subtheme was identified after repeated readings that may have been an underlying barrier. As this project did not include the patient's point of view it is hard to know for sure, but many comments identified a need for both parties, the provider and the patient, to provide each other permission to begin these conversations. The idea that both the patient and provider experience a lack of control over the situation or fear of the acceptance of the information may be preventing the start of these conversations:

> *"...it will take broad input from various providers to come up with a protocol that allows providers to be themselves and comfortable with the conversation.... some patients refuse to discuss prognosis at end of life."*

4.4c Documentation is vital for communication

Participant comments indicated there is an apparent lack of systematic approach and approved upon location in the electronic medical record to document when discussions occur with patients regarding Goals-of-Care and end of life wishes. Even when discussions are completed, they often are placed within the progress note of a visit and difficult to find within the electronic medical record. The following participant quotes highlight the various approaches being used to document and communicate Goals-of-Care Discussions:

> *"Advanced Directives have a dedicated place in our EMR and GOC discussions would be in progress/clinical notes."*

> *"I have a personal dot phrase that I use when putting patients on hospice. Regarding life sustaining treatment, it gets put in a regular clinic note. I have tried to use the documentation for GOC that already exists and find it clunky and too much extra work." "We have a goals of care dot phrase." "I send a message to the primary onc team and let them know I initiated or reiterated the conversation."*
>
> *"I don't do it formally".*

All of these variations in responses to methods of documentation clearly show there is a need to formalize the process and have a centralized location of documentation for all parts of the Goals-of-Care Discussions which include advanced directives. This would serve as a way to communicate patient wishes and would be beneficial for all members of the care team to be able to access easily: *"Documentation of GOC discussions certainly can aid communication across patient care teams."*

4.4d Varied opinions about protocol development

Another aspect of this project was to gain input from major stakeholders at the facilities for developing a protocol for conducting Goals-of-Care Discussions, as this could promote buy-in. The support for developing a protocol at this facility varied amongst participants. The feedback provided was in many ways tied into the previously mentioned theme about lack of time:

> *"I am all for discussing GOC with patients and obviously documenting the outcome in your clinic notes, but I suspect mandating a specific protocol may make this another group of mouse clicks in EPIC that annoys providers."*

Documentation was perceived as extra work and currently ineffective given that it is not in a central place within the electronic medical record. According to one participant: *"Goals of Care* *add more time into clinic visits. Adding more documentation and 'clicks' to EPIC also places a burden on the care provider"* It was repeatedly emphasized that the locations of documentation would need to carry throughout the health system with a dedicated spot within the electronic health record. Suggestions were made for standardized templates with a narrative section with reminders of what to discuss and how to personalize the discussion. It was felt that smart phrases may facilitate the ability to document faster and could use "pop up" words to trigger the documentation within the system such as "mets". There would also need to be metrics in place to monitor for completion of this documentation: *"I am all for discussing GOC with patients and obviously documenting the outcome in your clinic notes, but I suspect mandating a specific protocol may make this another group of mouse clicks in EPIC that annoys providers."*

Input was also sought about the created videos, as it was envisioned that they could be part of the future site protocol. One participant stated:

> *"I appreciate the effort that it must have taken to put these videos together, but I feel they missed the mark in several ways. It may be more helpful to talk about what is important to patients if their cancer progresses or they are at the end of life. Much of the video seemed to be trying to convince people that having GOC were important rather than planting seeds of open-ended questions that would get people to think (providers too). I think it is a mistake to use the word futility and to even mention resource utilization as a reason to have these discussions. The video did not address emotion at all and this cannot be ignored."*

Although this highlights areas that may need to be improved with the videos, an important aspect is that they were not meant to replace the actual one-on-one conversations between patient and

providers. Instead, they were meant to open the door to opportunities to discuss all aspects of concern for patients whether actual or perceived, emotional or physical, clear or vague.
An alternative opinion was offered, *"I believe this would open the lines of communication between providers and their families. Use of the video stimulates conversations between family members."* Another supporter stated, *"I think it is a positive way to start the conversation without scaring or coercing patients or their loved ones. Really lovely approach that is easy to follow and understand."*

Many respondents expressed the need for a system to be in place (such as a protocol) to *"simply encourage me to be more proactive"* and how important it was to "*have additional ways to broach the topic with patients."* As one provider stated, *"a majority of patients are not having their goals met at the end of life, likely because providers did not previously discuss options with them or identify goals with them."*

4.4e Us versus them

One noted theme that appeared to be a single thread throughout is whose responsibility is it to have these conversations. A consistent aspect of comfort level fell in the identified discourse of whose primary responsibility it was to initiate Goals-of-Care Discussions. Many noted that it is not only difficult for the patient to hear, but also can be emotionally difficult for the provider initiating the conversations. As the primary oncologist relationship with the patient was felt to be of utmost importance, it was consistently reported that they should be the ones to initiate Goals-of-Care Discussions and then a referral can be made to palliative care to carry on the conversation with more detail and attention to patients wishes.

It was suggested that these conversations begin at the time of diagnosis during an introduction to the clinic by the primary oncology team: "*I would love it if we could have this* *discussion with every single patient before they start treatment for a terminal illness such as cancer."* The conversations could then be revisited "*in an open-ended way during subsequent visits*." One participant described the importance of revisiting Goals-of-Care Discussions:

> *"There should be a clear message to providers that, while complete GOC conversations are important, partial conversations are better than none…. Sometimes advocating for every aspect of GOC discussion can prevent any discussion from happening."*

In the literature and at the practice site there is an ongoing "push" for increased referrals to palliative care as an attempt to improve the quality of care at the end of life. However, overwhelmingly, participants supported the primary oncology team to be the ones to initiate these Goals-of-Care Discussions. One provider put it this way: *"Goals of care discussions are the responsibility and the privilege of the treating oncologist, NOT a palliative care team."* Another stated in response to their support of the videos that, *"If they (patients) have a good rapport with their provider and are accustomed to open discussion, I don't know that the video would add extra benefit to the situation."* This statement again shows a support for the primary oncology team and not necessarily that of palliative care.

Chapter 5 Discussion

With advancements in research and an increase in treatments of cancer with targeted chemotherapy and immunotherapy, more and more people are living with advanced cancer. The number of people that will be living with cancer is projected to reach nearly 19 million by 2024 (Brooke & Swartz, 2017). Given this, along with the aging of this patient population, comes multiple chronic illnesses and comorbidities along with the physical, social, and financial symptom burden of the diagnosis of cancer. Palliative care is positioned to be very important in the partnership with oncology providers to improve quality of life. Organizations such as the Institute of Medicine, the World Health Organization, the National Quality Forum, the American Society of Clinical Oncology (ASCO), the Commission on Cancer, the National Comprehensive Cancer Network (NCCN), in addition to others have now called for an improvement in palliative care services and even more importantly are recommending the integration of palliative care into routine care of patients with serious illness such as cancer. ASCO has most clearly stated this as follows: "combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden (Rabow et al., 2013). With this paper, it is suggested that palliative care is only one piece of the Goals-of-Care Discussions that needs to occur with every individual diagnosed with a life limiting disease such as advanced cancer.

5.1 Discussion of Quantitative Results

The ultimate goals of this project were to identify barriers to initiating Goals-of-Care Discussions for patients with a life limiting cancer diagnosis to create provider education and an icebreaker tool (the white board scribe videos) to begin to break down these barriers. This project's N=66 out of about 150 providers at the site indicates interest in this topic.

Those that volunteered to take part in this quality improvement project were given a pre-test and post-test survey to assess their self-efficacy for conducting Goals-of-Care Discussions. They were shown two five-minute white board scribe videos. The first video for educating and clarifying Goals-of-Care Discussions for provider education. The second one was designed to be for patients to view to help educate them and prompt them with choices and questions for their healthcare provider. It was envisioned to be a way to help break down the awkwardness and difficulty with initiating Goals-of-Care Discussions that the literature has identified as being present with most providers caring for terminally ill patients. It was interesting to note that the majority of respondents scored themselves high on self-efficacy at baseline but still showed statistically significant score improvements after viewing these short five-minute videos. In fact, the overall mean score increased from 3.99 to 4.32, demonstrating a close to neutral report of being confident improving to a confident level.

There are a number of studies that have attempted to improve healthcare providers abilities in having these very difficult but vitally important conversations. One such method is called the “SPIKES” framework for approaching difficult conversations with patients. It includes the scene (S), ensuring a private place to talk; perception (P), finding out what the patient knows about their disease and prognosis; invitation (I), getting permission to share information with them; knowledge (K), letting patients know if bad news is coming; empathy (E), responding empathetically to their emotion; summarize (S), summarizing the discussion (Dunlay & Strand, 2016). Another study developed a “Goals of Care Ambulatory Resident Education (GOCARE)” that coordinate a curriculum during physician residency that showed statistical significance in improving residents comfort level in having discussions around end of life and advanced care planning post course (Berns et al., 2017).

In addition to improvements in self-efficacy for Goals-of-Care Discussions, only 3 items on the self-efficacy scale did not demonstrate statistically significant improvements: 1) finding time to have the discussions 2) clarifying the disease and prognosis, and 3) responding empathetically. While the education could be augmented to address clarifying and empathy, it cannot fix the lack of time participants reported in the open-ended questions. It is clear that lack of time must be considered when developing a site protocol for Goals-of-Care Discussions. Providers agree to the importance of these conversations but continue to report that given constraints of the clinic and how these conversations can become quite involved, they often do not have time to initiate them. If patients were afforded the ability to view a video similar to the one created for this project, this may help alleviate time barriers. For example, prior to their clinic visit, patients could view it on an iPad in the exam room before the provider enters or in the waiting room. This may offer patients the ability to begin making choices and to be more prepared to discuss with their provider. It would offer a starting point.

Results also reflected that 63% of participants reported conducting Goals-of-Care Discussions either “very often” or “often” in their practice; however, personal experience and colleague discussions indicate practice dictates that this is not occurring or at least is not being documented. Creating or adopting a protocol on conducting and documenting Goals-of-Care Discussions may help address this apparent mismatch in self-report and actual practice. Support for creating a site protocol at this project site was overwhelmingly positive (84.8% in favor of protocol development. Most of the literature is approaching the method of increasing the frequency of Goals-of-Care Discussions from different angles whether it be from an increase in education of communication styles or breaking down barriers such as fear of failure or diminished hope by imparting these talks with patients. Few studies show a developed protocol.

One Canadian study, by Raskin et al. (2016) approached it strictly from a documentation standpoint. They looked at both medical oncologists as well as palliative care clinicians to see what aspects, if any, of a Goals-of-Care Discussion, prognosis, or treatment benefit took place, whether it be in symptom management, DNR, or advanced care directives. It was shown that the medical oncologist documented Goals-of-Care Discussions in only 4% of patients (n=222). They documented the fact that the disease was incurable in two thirds of the patients and the amount of treatment benefit in one third. Of these patients less than half were referred to palliative care (Raskin et al, 2016). Given the overwhelming support for a protocol development in this study (84.8%) it is felt that with the proper education and tools in place for comprehensive documentation that the frequency of much needed Goals-of-Care Discussions will increase.

5.2 Discussion of Qualitative Results

Not surprisingly so, as previously noted, much of the qualitative themes were broken down into lack of time, provider discomfort, documentation practices/preferences, varied opinions about protocol development, and the discourse between whose job it is to start these conversations: palliative care or primary oncologist.

Although the reports from the Institute of Medicine (IOM) both in 2014 and as early as 1997 (*Approaching death: Improving care at the end of life, IOM 1997*) have shown the importance of improving care at the end of life and not only for improvement in quality of life but also for cost containment, the implementation of Goals-of-Care Discussions continue to remain scarce. The IOM put together a committee of 21 members of diverse backgrounds including nursing, medicine, law, bioethics, social sciences, epidemiology, economics, geriatrics and pediatrics. They were given the task to look at the issues with end-of-life care with a broad lens that would include clinical care and delivery, resources and workforce, economics, spirituality, public engagement, and challenges that may be met with subgroups such as children, those with low health literacy, and those from multiple identities of race and ethnicity. Specifically, their goal was to look at the current progress being done, evaluate strategies that are being utilized to integrate care at the end of life from a team-based approach, develop recommendations for changes in policy, finance, payment practices, workforce development, research, clinical and supportive care, and then disseminate their findings for increase in engagement. Task forces such as this one developed by the IOM is a start. Their studies identified that health professionals are not always adequately prepared to deliver palliative care and that there needs to be an integration of specialty practice in hospice and palliative care medicine collaboratively with primary oncology when caring for patients facing a life limiting disease. They also identified the need for public education and engagement about end-of-life care to begin to normalize conversations about death and dying (Meghani & Hinds, 2015).

With the noted discourse amongst the participants in this study about whose “job” it is to have these discussions, it is perhaps important for healthcare providers to approach patient with a life limiting disease as a team with early integration of specialties such as hospice and palliative with the ultimate goal in improving the quality of life until the end. Frequent Goals-of-Care Discussions are needed between providers and patients. These conversations can occur with other members of the healthcare team as well, such as nursing staff, clergy, social work, and counselors. This was suggested in the open-ended question responses: to have separate Goals-of-Care Discussions appointments to provide the attention needed (and also alleviate the time barrier) and to have other support persons there to continue to work with patients. Most patients nearing the end of life may find it difficult to make their own decisions without guidance. Further, they often receive acute hospital care from physicians or providers that do not know them (i.e. hospitalists). It would be more helpful if Goals-of-Care Discussions were initiated earlier by a member of their care team who sees them regularly. Thus, developing a protocol to ensure Goals-of-Care Discussions occur is paramount. Further, this protocol should include specific guidance for documentation practices within the patient's chart. This will help ensure that all team members have access to patients wishes so they can be upheld even when the patient can no longer communicate them. Research shows that of individuals that have communicated their preferences at the end of life, most choose care focused on alleviating pain and suffering (Kahn, 2014). Having wishes documented would help to improve quality of life. Yet, the qualitative findings of this study indicate that providers are documenting patients' wishes in various places, limiting communication across settings. Findings also showed that providers, in general, supported having a designated place for documenting patient wishes and offered ideas for consideration (such as use of dot phrases or templates).

Many physicians and oncology providers, as well as patients, often equate the concept of *"hope"* as *"hope for a cure."* Therefore, by definition to be diagnosed with a terminal illness meant to be without hope. The providers then find that this places them in a quandary where they are trying to balance the open disclosure of a poor prognosis with realistic expectations with that of maintaining a sense of hope in their patients. One respondent stated, "*If the provider initiates then the patient thinks that the provider is giving hope...I think providers feeling like they have failed can be a barrier to having these discussions."* Being human, most patients will say that they hope to get better. According to a 16th century French author Francois de La Rochefoucauld, "Hope, deceitful as it is, serves at least to lead us to the end of life along an agreeable road." (Elliot, 2013).

A theme identified as a barrier to Goals-of-Care Discussions was determining whose responsibility it is to initiate these conversations. There appeared to be a discourse between the role belonging to the primary medical oncologist versus palliative care. Many used the terms "*us*" and "*them*" and this promoted a feeling of lack of team approach. Protocol development would need to incorporate all providers, both medical oncology and palliative care, to be involved in education and development. Support would need to be garnered for normalizing early Goals-of-Care Discussions, and findings indicated a preference for this to occur with the primary oncology provider with the introduction of the concept of palliative care at the time of diagnosis. As identified at this institution overwhelmingly (93.8%) would be in favor of a shared responsibility between the primary oncologist and the palliative care team but it would be up to the primary oncologist to initiate the discussions.

Palliative care clinicians are uniquely positioned and trained to care for patients with advanced cancer who are experiencing symptoms of fatigue, pain, weakness, loss of appetite, and lack of energy. Along with this, approximately 30% of patients receiving palliative care also experience some combination of depression, anxiety, and difficulties with adjusting to their diagnosis (Greer, 2013). The trouble is, as represented in the findings of this project, there is often a misconception of whose role it is to manage such symptoms.

Typically, and rightly so, the focus of the oncology care team is on establishing an accurate diagnosis, staging of disease, and development of the plan of treatment. Given this role, many oncology providers do not refer to palliative care early enough and often wait until the symptoms are difficult to control and/or the patient is nearing the end of life (Greer, 2013). This role blurring often results in a missed opportunity for the patient to receive the most optimal care and often they receive care they do not want as there has not been a proper dedicated Goals-of-Care Discussion.

According to the 2014 IOM report, the poor adherence to completing advanced care planning and conducting end of life discussions often occurs because both the providers and the patients/families are waiting for the other to initiate the discussions (Meghani & Hinds, 2015). This project has begun to shed light on the benefits of Goals-of-Care Discussions and what can be done to begin to break down barriers that are currently preventing Goals-of-Care Discussions to occur early on in a patient's cancer journey. These discussions, when performed, have been shown to improve patient sense of autonomy, reduce the length and number of hospitalizations by avoiding unwanted aggressive treatments, have lowered the rates of ventilation, resuscitation, and intensive care unit admissions. Not only does this decrease the cost of end-of-life care but also improves overall quality of life in patients with a life limiting prognosis (Bestivina & Polite, 2017). While participants in this project did acknowledge the importance of Goals-of-Care Discussions, there was also discomfort expressed about actually conducting them. Through triangulation of data, it was suggested that this can be overcome with education, which showed to improve self-efficacy in this project.

Our current federal, state, and private insurance and health care delivery methods incentivize care that involves high-technology, high acuity and post-acute medical services. Fee for service Medicare, for example, results in an increase in use of services that include more transitions among care settings and late enrollment in hospice (Meghani & Hinds, 2015). This is happening despite the fact that most patients report preferring to receive care at end of life in their own homes or communities. The IOM report has recognized this and has recommended a system change that would support high quality end of life care consistent with patients' expressed desires for care (Meghani & Hinds, 2015). Research supports that Goals-of-Care Discussions should not occur in a vacuum. When they are done effectively, they are "exploratory, conversational, and longitudinal" and more comprehensive when done outside of an urgent or life-threatening situation to avoid the feeling of being pressured or transactional. LeBlanc et al (2020) stated that "they should begin at the kitchen table, continue at the clinic, and evolve over time" (p. 2). This is best facilitated by having a dedicated billing code for these discussions. Being able to bill for Goals-of-Care Discussions can help promote the practice of having separate appointments for these discussions as suggested by participants as a way to overcome the time barrier.

Most Americans continue to lack knowledge about choices available to them if they have a life limiting disease. They do not understand the importance of engaging in meaningful dialogue with their family, friends, and healthcare providers to communicate their preferences, values, and what is important to them now while they are able to have these conversations. They do not understand they have the right to demand high quality care that is compassionate and supportive, but that may differ from that of a curative approach with aggressive care. It is for this reason that education is needed. The white board scribe videos presented in this project present a start towards achieving his goal. While participants provided feedback to help improve the patient video, overall, they expressed support for this strategy as it would serve as an ice breaker (to address provider discomfort barrier) and help prepare patients to participate meaningfully in Goals-of-Care Discussions (to address time barrier). Perhaps allowing our patients to view this video at the time of diagnosis to begin to educate them as to choices they have during their disease. As stated, this video would be meant to introduce the concept and educate the patients but is not meant to replace the face-to-face conversations they should have with their health care providers.

5.3 Successes and Limitations

Successes of this project include validity and high reliability of the Baughman Self-Efficacy tool, availability to potential volunteers for survey with success of recruitment of a large enough sample size capable of detecting statistically significant changes, as well as being able to recruit providers representing MD, NP, and PA well. There was also support from the participating clinical sites. It is unclear whether this was a success or limitation, but this project sparked a lot of controversy at the participating sites as to the unspoken discourse between primary oncologist providers and palliative care as well as physician and Advanced Practice Provider (APP). Perhaps this should be viewed as a success as now there is more attention and light being shed as to what the struggles may have been with the low referrals to palliative care for quite some time at this institution.

Limitations noted in this project include lack of gender and racial/ethnic diversity amongst the participants. It would be interesting to repeat this project at a different setting such as a large oncology independent practice or a more rural setting. Next, data for this project was collected immediately pre- and post-education, therefore, it is not known if improvements in self-efficacy are sustained over time. Another limitation was the lack of patient input as to the effectiveness of the ice breaker video. Gaining this insight in a future project may place a better understanding on what it would take to help patients better understand the choices that are available to them during their cancer journey and how to help them engage in a shared decision-making opportunity with their health professional. Finally, a limitation is the sole focus on Goals-of-Care Discussions only with oncology patients. It may be helpful to consider other opportunities with other disease groups such as heart failure or neurodegenerative disease which also have a life limiting prognosis to investigate end of life care and their approach to these important conversations.

5.4 Recommendations for Clinical Practice

This project has shown that even with a short video such as the one presented to this sample, there can be a statistically significant impact made in self-efficacy among providers for conducting the very important conversations about choices available to patients at the end of life. As has been stated, there is often hesitancy for providers to begin Goals-of-Care Discussions whether it be for fear of suppressing hope or giving up on the patient or lack of time available in clinic or knowing whose role it is to begin these conversations. Developing a video that can be shown to patients at the time of diagnosis to introduce them to what it means to have a life limiting diagnosis and what choices are available to them for end-of-life care may help overcome this provider discomfort and open the door to both the patient and provider to begin the conversation. There is potential for this strategy to be used with oncology patients, as well as those with other life limiting diseases. This may also be a means to overcoming health literacy as a barrier for patients and their understanding of their prognosis and care choices available.

As documentation practices were found to have varied greatly across the health system, it would help to develop a protocol for a centralized area within the electronic medical record where Goals-of-Care Discussions can be documented. This would allow all health care providers caring for a patient to have access to documented patient wishes. This will be helpful for those in the acute care setting such as the ED or ICU to know where a patient's choices stand as far as desired care. A 2011 qualitative study looked at documentation practices of discussion in the final weeks of life and there were definite variations in what was discussed and how detailed each discussion was documented. The concern was that if patients move across the healthcare system to other care providers that the lack of details may not be helpful if they are not able to speak for themselves with regards to end of life preferences (Cox, 2011).

As noted, it is important that these conversations occur early and often. With each subsequent visit to address Goals-of-Care, additional documentation in the same centralized location could occur. To develop this protocol, it will take buy-in from all participating stakeholders as well as cooperation from the developers of the electronic medical record to help develop this central location. It would then require system wide education so that all healthcare providers are aware.

5.5 Recommendations for Future Projects and Research

Protocol Development. As stated above, it is recommended to consider protocol development for conducting Goals-of-Care Discussions. To do this would first require a patient centered project to address what their needs are for conducting this type of conversation. As was stated by one participant, *"There are some patients who do not want to have the conversations and there is nothing that will change that. For* patients *that are hesitant or in denial about their situation, it will likely help them to be open to a conversation."* This creates a myriad of questions to answer through a patient centered project: How do we address their choices for care? Would they be open to allowing a surrogate that is designated to talk with about what we can do as healthcare providers to provide the type of support that they need even if they are uncomfortable in discussing it? It should also include asking patients if the video or another type of icebreaker is helpful to at least start the conversations.

Cost of Futile Care. The American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative has identified quality metrics for improvement in end-of-life care.

These include no chemotherapy in the last 14 days of life and enrollment in hospice at an appropriate interval of time which includes greater than 7 days (Greer, 2013). This will take a coordinated effort on the part of the primary oncology team with palliative care clinicians to conduct Goals-of-Care Discussions earlier and more often so that the desires of the patient can be met. In addition to the desires of the patient, it is noted that with chemotherapy and inpatient admissions near the end of life, there is a delay in referrals to hospice. Future research should focus on evaluating the end-of-life cost of care for patients that have participated in Goals-of-Care Discussions versus those that have not expressed their end of life wishes. The Lancet Oncology Commission reported that "cancer is in a crisis" as it is driven by a "culture of excess and futile care" (Carrieri, 2020, p. 2754). The cost of futile care in relationship to these discussions has not been sufficiently investigated. It is thought that perhaps involving palliative care earlier in standard oncology care using the co-management model has the potential to reduce hospital costs by fewer ED visits and inpatient hospital stays, as well as minimizing the high costs and potential side effects of near-death chemotherapy (Greer, 2013). Thus, this investigation focus would aim to improve quality of life for patients with a life limiting disease.

Diversity and Goals-of-Care. Attitudes and practices surrounding death vary amongst cultures. With the unspoken promise of modern medicine to defeat illness and death, there has been a loss of rituals and cultures surrounding death and a loss of the ability to make sense of death and suffering as a part of life. Carrieri et al (2020) suggested that the oncologist provider take on the role of *amicus mortis* (friend of death). Their article speaks of the oncology provider as helping patients at the end of life through methods of palliation and support with physical and psychosocial resources. Linking patients not only to palliative care and hospice, but also to cultural and community resources that would be in concordance to their wishes is important

(Carrieri et al, 2020). This then indicates the need for further research that looks at the cultural differences in patients with a life limiting disease. The following question requires attention: Are we meeting their needs adequately enough by referring to hospice or palliative care or are there other culturally diverse conditions that should be explored to ensure that we are addressing what is important to patients and families at end of life?

5.6 Conclusion

Overall, this project was a success in that it opened up conversations at the cancer center site that needed to happen. Inpatient hospitalists had been reporting for quite some time that patients were presenting to the ED never having been told that their diagnosis was life limiting and not understanding the choices that were available to them for end of life. Often, because of these patients have been receiving inpatient acute care that is aggressive and expensive when research shows that the majority of patients wish to die at home surrounded by loved ones instead of in the ICU. Formal recording and documentation of these discussions is important and should be centralized within the electronic medical record so that all healthcare providers treating a patient can know of these conversations and support the patient's choices.

Utilization of palliative care early on has been shown to improve patient care at end of life but referral to palliative care is not always done. A common misunderstanding is that palliative care and Goals-of-Care Discussions are one in the same when in fact the very skilled and educated approach to symptom management at end of life by palliative care represents only one aspect of a comprehensive Goals-of-Care Discussion. A team approach to a patient centered plan for what is important to a patient is key.

This project involved educating oncology providers using short white board scribe videos. Results showed improved self-efficacy for Goals-of-Care Discussions, even after viewing just two short videos. This approach is not only feasible for use as ongoing education, but also desirable because it can be offered online to busy providers who do not typically have time to attend classes. Through also collecting qualitative data, providers were able to offer insight about ways to improve the videos. Open-ended responses also yielded helpful information about barriers to Goals-of-Care Discussions (namely lack of provider time and discomfort) that are important to consider when developing a site protocol about conducting Goals-of-Care Discussions. Insight was also gained on documenting these crucial conversations, with documentation key to upholding wishes across settings.

As Dr. Paul Kalnithi, a surgeon diagnosed with lung cancer and author of the book "When Breath Becomes Air," said so well: "...the physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence (Kalanithi, 2016, page 166)". This project aimed to create that dialogue and allow patients and providers the means to open up doors to understanding what quality care means at end of life.

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Appendix A: Demographic Survey Items

Please answer each question below:

What is your age?

- ☐ 20-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50-59 years
- ☐ 60 or more years

What gender do you identify with most?

- ☐ Female
- ☐ Male

What is your race/ethnicity?

- ☐ Hispanic or Latino
- ☐ Black or African American
- ☐ White or Caucasian
- ☐ Asian/ Native Hawaiian/ Pacific Islander
- ☐ American Indian or Alaska native
- ☐ Other: _____________ (type in)

What is your Disease Specialty?

- ☐ Brain
- ☐ Breast
- ☐ Thoracic
- ☐ GI
- ☐ GU
- ☐ Malignant Heme
- ☐ Other: ____________ (type in)

What type of degree/license do you have?

- ☐ Physician
- ☐ Physician Assistant
- ☐ Nurse Practitioner
- ☐ Other: ____________(type in)

How many years of experience do you have in healthcare?

- ☐ 1-4 years

- ☐ 5-9 years
- ☐ 10-14 years
- ☐ 15-20 years
- ☐ 21-25 years
- ☐ >25 years

How many years of experience do you have in oncology?

- ☐ 1-4 years
- ☐ 5-9 years
- ☐ 10-14 years
- ☐ 15-20 years
- ☐ 21-25 years
- ☐ >25 years

How often do you have Goals-of-Care Discussions with your patients?

- ☐ Very often
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

What percentage of your patients have a terminal diagnosis? ______ (type in)

What role do you feel Palliative Care plays in having Goals-of-Care Discussions?

- ☐ No role at all
- ☐ Palliative care should be the ones to have these conversations
- ☐ Shared responsibility and palliative care should initiate
- ☐ Shared responsibility and I (as primary provider) should initiate

Appendix B: Advance Care Planning Self-Efficacy (ACP-SE) Scale

On a scale from 1 to 5 where 1 equals not at all confident and 5 equals very confident, how confident are you that you can do the following for patients?

	Not at all confident			Very confident	
1. Find the time to discuss the patient's prognosis, preferences and care plan with the patient	1	2	3	4	5
2. Determine how much the patient wants to know about the prognosis	1	2	3	4	5
3. Determine the level of involvement the patient wants in decision-making	1	2	3	4	5
4. Determine who else (e.g., family members) the patient would like to be involved in decision-making	1	2	3	4	5
5. Provide the desired level of information and guidance needed to help the patient in decision-making	1	2	3	4	5
6. Describe the pros and cons of different life-sustaining treatments	1	2	3	4	5
7. Determine the patient's specific wishes for types of medical treatment	1	2	3	4	5
8. Discuss and negotiate individualized treatment goals and plans with patient	1	2	3	4	5
9. Ensure that patient's treatment preferences will be honored at your facility	1	2	3	4	5

10. Ensure that patient’s treatment preferences will be honored at a hospital if patient is hospitalized	1	2	3	4	5
11. Discuss how to complete a living will with the patient	1	2	3	4	5
12. Determine when there should be a shift in care goals	1	2	3	4	5
13. Reassess the patient’s wishes when a shift in care goals is needed	1	2	3	4	5
14. Openly discuss uncertainty with patient when it exists	1	2	3	4	5
15. Educate patient and clarify any misperceptions about the disease or prognosis	1	2	3	4	5
16. Respond empathetically to patient’s and family’s concerns	1	2	3	4	5
17. Communicate “bad news” to patients and their families	1	2	3	4	5
18. Engage patients in advance care planning conversations	1	2	3	4	5

Note that the last item, R, is a general item that includes all advance care planning and not part of the scale. It can be used for comparison to the scale.

Citation: Baughman KR, Ludwick R, Fischbein R, McCormick K, Meeker, Hewit M, Drost J, Kropp D. Development of a scale to assess physician advance care planning self-efficacy. American Journal of Hospice and Palliative Medicine. 2016 Jan 12. [Epub ahead of print]

Please send the citation for any research products (dissertation, thesis, journal article, book, book chapter, report, etc.) that result from use of the scale to Kristin Baughman at kbaughma@neomed.edu.

Appendix C: Permission for Use of Advance Care Planning Self-Efficacy (ACP-SE) Scale

Apr 6, 2020, 3:05 PM

Kris Baughman

to "Ruth, **me**

Hi Victoria,
We would be happy to share our scale with you (see attached file). We only ask that you cite us as you disseminate your results.
We scored the scale by simply taking the average of the items. We did not have any weights for the items.
I have copied my colleague, Ruth Ludwick, on this email since she has years of experience working with nurse practitioners. She will be happy to see another nursing project!
Please let us know how your project goes. We would love to hear more about it!
Best wishes,
Kris

Apr 7, 2020, 3:33

Ruth Ludwick

to Kris, me

Hi Victoria

Ruth here. Just to echo Kris's best wishes and to say if you need a nursing perspective I am happy to be a sounding board--not to replace faculty but just extra help if needed.

It would be interesting to see the diff between the 2 types of practitioners. We have had several DNP students express using as a pre-post. We have not seen anything in press in lit yet. Might try dissertation and theses abstracts to see the project used--even though not published in peer reviewed lit.

Ruth

Ruth Ludwick, PhD, RN-BC, APRN-CNS, FAAN
Adjunct Graduate Faculty, Northeast Ohio Medical University
Professor Emeritus, Kent State University, College of Nursing
Independent Consultant Personal email: rludwick@kent.edu

Appendix D: Provider Level of Support Item

Please indicate your level of support for having a protocol on initiating and documenting Goals-of-Care Discussions:

○ I do not support this at all. Type in your concerns:

○ I'm not sure if I support this. Type in your concerns:

○ I do support this. Type in any thoughts you want to share:

Appendix E: Post-Test Open-Ended Questions

1. Please share your thoughts and feedback about the education you just received.

2. What do you think was the most important thing you learned?

3. How do you think this education should continue to be used at our facility?

4. Please share your thoughts and feedback about the scribing video for use to introduce patients to Goals-of-Care Discussions.

5. What do you feel are the barriers to initiating and documenting Goals-of-Care Discussions and how do you think these barriers can be overcome?

6. How do you currently document advanced directives and end of life preferences?

7. How do you think time constraints affect whether Goals-of-Care Discussions occur? Do you have a suggestion of how to overcome time as a barrier?

8. Please discuss your preferences for documenting patients' Goals-of-Care.

9. What are your thoughts about using a dot phrase embedded in the EHR as a way to document and communicate patients' Goals-of-Care preferences?

10. Do you think use of the Surprise Question criteria would be helpful to include in a protocol to guide providers in identifying when to initiate Goals-of-Care Discussions? Please explain.

11. Please provide any other input you have to assist in development of a protocol on Goals-of-Care Discussions.

APPENDIX F: IRB APPROVAL DUKE

DukeHealth
Institutional Review Board

DUHS INSTITUTIONAL REVIEW BOARD DECLARATION OF EXEMPTION FROM IRB REVIEW

The DUHS IRB has determined that the following protocol meets the criteria for a declaration of exemption from further IRB review as described in 45 CFR 46.101(b), 45 CFR 46.102 (f), or 45 CFR 46.102 (d), satisfies the Privacy Rule as described in 45 CFR 164.512(i), and satisfies Food and Drug Administration regulations as described in 21 CFR 56.104, where applicable.

Protocol ID: Pro00105941
Reference ID: Pro00105941-INIT-1.0
Protocol Title: Breaking Down Barriers to Early Goals-of-Care Discussions with Terminally Ill Cancer Patients
Principal Investigator: Deborah Allen
Review Date: June 04, 2020
Expiration Date: **Does not expire*
Exempt Category: Category 2: Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: i. The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; ii. Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or iii. The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by .111(a)(7).

*This Declaration of Exemption from further IRB Review is in effect from June 04, 2020 and does not expire. However, changes to the proposed research will require an amendment requesting re-review for exemption. Reportable serious adverse events and unanticipated problems related to the research that place subjects or others at risk of physical, psychological, economic, or social harm must be promptly reported to the IRB and will result in reconsideration of the activityâ s exempt status.

DUHS Institutional Review Board
2424 Erwin Rd | Suite 405 | Durham, NC | 919.668.5111 Federalwide Assurance No: FWA 00009025

APPENDIX F: UNCC IRB APPROVAL

From: IRB <uncc-irb@uncc.edu>

Subject: IRB Notice - 19-0834

Date: July 15, 2020 at 1:24:25 PM EDT

To: <vpoilluc@uncc.edu>, <kpower15@uncc.edu>

Cc: <uncc-irbis@uncc.edu>

To: Victoria Poillucci
School of Nursing

From: Office of Research Protections and Integrity

Date: 7/15/2020
RE: Notice of Approval of Exemption with No End Date
Exemption Category: 2.Survey, interview, public observation
Study #: 19-0834

Study Title: Breaking Down Barriers to Early Goals-of-Care Discussions with Terminally Ill Cancer Patients

This submission has been reviewed by the Office of Research Protections and Integrity (ORPI) and was determined to meet the Exempt category cited above under 45 CFR 46.104(d). This determination has no expiration or end date and is not subject to an annual continuing review. **However, you are required to obtain IRB approval for all changes to any aspect of this study before they can be implemented.**

Study Notes:

- Per University mandate in response to the ongoing Coronavirus Disease 2019 (COVID-19) outbreak, all Human Subjects Research activities involving on-campus implementation **and/or** direct person-to-person contact should not proceed until University restrictions are lifted.
- Restoring and restarting direct person-to-person Human Subjects Research activities, must have University-level approval. Refer to the Research Restart and Restoration Task Force Report and the Office of Research Protections and Integrity guidelines.
- Further, activities occurring off-campus must adhere to local, state, and federal restrictions (including stay-at-home orders) as well as public health requirements for the size of groups/gatherings, social distancing, hygiene, and sanitization, etc.
- Protocol Modifications are needed to adjust data collection procedures to remote data collection (e.g., phone, online or virtual).

The Investigator Responsibilities listed below apply to this study only. Carefully review the Investigator Responsibilities.

Study Description:

Research shows that aggressive treatments are occurring despite what patients express as their wishes for end of life. This mismatch shows that Goals-of-Care Discussions between patients and providers are not commonly occurring. Interventions to facilitate these discussions in practice are vital to ensure that both the patient and provider are in agreement with the desired plan of care. It has been observed in outpatient oncology clinic that Goals-of-Care Discussions do not occur early enough, or in some cases do not occur at all. Patients are presenting to the ED never having been told they are terminal or having discussed end of life wishes with their provider. This then leaves hospitalists, who have never met the patient because they provide care solely in the inpatient setting, responsible to discuss end of life and goals of care. Study will involve pretest, two educational videos lasting about 2 minutes each and a posttest-for oncology care providers.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=19-0834.

Investigator's Responsibilities:

The above-cited determination has no expiration or end date and is not subject to annual continuing review.

However, the Principal Investigator needs to comply with the following responsibilities:

1. Modifications **must** be submitted for review and approval before implementing the modification. This includes changes to study procedures, study materials, personnel, etc.
2. Data security procedures must follow procedures as approved in the protocol and in accordance with ITS Guidelines for Data Handling.
3. Promptly notify the IRB (uncc-irb@uncc.edu) of any adverse events or unanticipated risks to participants or others.
4. Complete the Closure eform via IRBIS once the study is complete.
5. Be aware that this study is now included in the Office of Research Protections and Integrity (ORPI) **Post-Approval Monitoring program** and may be selected for post-review monitoring at some point in the future.
6. Reply to ORPI post-review monitoring and administrative check-ins that will be conducted periodically to update ORPI as to the status of the study.
7. Three years (3) following this Exemption determination, ORPI will request a study status update (active/not active).

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).