An Educational Intervention to Increase Diabetic Patients' Readiness to Discuss Advance Directives in Primary Care

by

Sheila M. Fuller

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Sarah M Gilbert
Dr. Sarah M. Gilbert
Dissertation Advisor

April 27, 2020
Date

Dr. Katie R. Katz
Committee Member

April 27, 2020
Date

Wendy R Downey
Dr. Wendy R. Downey
Committee Member

April 27, 2020
Date

ABSTRACT

Diabetes is a chronic condition with an unpredictable disease trajectory associated with multiple complications and shortened life expectancy. Diabetic patients require frequent office visits to monitor their disease, which also provide an excellent opportunity for patients to discuss their potential disease progression and options for care in the future, advance care planning. The purpose of this study was to explore whether providing advance care planning education to diabetic patients in the primary care setting, earlier in their disease process, would improve their readiness to discuss advance directives with their family and providers prior to experiencing a health crisis. A pretest-posttest design involving a sample of N = 34 adult, diabetic patients presenting for routine office visits compared patients' readiness to discuss advance directives with the Advance Care Planning Engagement Survey, 4-item version, before and after receiving education using the Five Wishes® advance directive form. The mean pretest advance care planning readiness score (*M* = 15, *SD* ± 4 Likert points) increased (*M* = 17, *SD* ± 3 points) after receiving education. The increase in readiness led to 32% of the sample completing the Five Wishes® form within 2 weeks and an additional 56% intending to complete a form within 3 months. Providing advance care planning education to diabetic patients during routine office visits does improve their readiness to discuss advance directives with family and providers.

Sheila M. Fuller, DNP

School of Nursing, 2020

Radford University

DEDICATION

I would like to dedicate this final project to my incredibly supportive husband, Mark Alan Fuller, whose love and support have been instrumental in my ability to focus so fully on the success of this Doctor of Nursing Practice Project. I also want to dedicate this work in memory of my loving father, William R. Caulfield, Jr., who always told me, “no one’s better than you,” and my brother, Kevin Caulfield, a former Emergency Department nurse, who left this world too soon. Both always brought love and laughter wherever they went.

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Chapter 1: Introduction

Diabetes Mellitus (DM) has been reported to be the most prevalent disease worldwide affecting 463 million people, responsible for 4.2 million deaths a year, an average of one death every eight seconds (International Diabetes Federation [IDF], 2019). The United States has followed only China and India as being among the countries with the largest number of people living with DM (IDF, 2019). This disease has affected 9.4% or 30.3 million Americans with Type 2 DM comprising 95% of all DM diagnoses (Centers for Disease Control and Prevention [CDC], 2017). Diabetes has been associated with complications of both macrovascular disease, atherosclerosis, and microvascular disease, including retinopathy, nephropathy, and neuropathy (Wexler, 2019). Diabetes complications increase the incidence of potentially life-threatening conditions including myocardial infarctions, cerebrovascular accidents (CVA), end-stage renal disease (ESRD), and lower extremity amputations (Wexler, 2019). These complications have also contributed to diabetes' reduced life expectancy, 12 years shorter for Type 1 DM and 8 years shorter for Type 2 DM diagnosed prior to age 40 (Dunning, Martin, Orford, & Orellana, 2018; Roper, Logan, & Tierney, 2001). Younger generations now make up a majority of the world's diabetic population. Seventy-two percent of diabetics worldwide are between the ages of 20 and 64 years old (IDF, 2019). The increased prevalence of DM among younger adults, below the age of 65, has led to earlier complications and subsequently earlier deaths (Dunning & Martin, 2017).

Diabetes, one of the top five chronic diseases, along with cardiovascular disease (CVD), cancer, CVA, and chronic obstructive pulmonary disease (COPD), has accounted for 62% of all deaths in the United States (Minino, 2011). According to the CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), 60% of U.S. adults have at least one chronic disease and 40% of U.S. adults have two or more chronic diseases (NCCDPHP, 2019). Data from the *National Health Interview Surveys* for 2000 and 2010 indicated the number of adults aged 45 to 64 years old diagnosed with multiple chronic diseases has increased by 5% for both genders across all racial and ethnic groups (Freid, Bernstein, & Bush, 2012). The 2012 survey indicated that the number of adults diagnosed with multiple chronic diseases continues to climb, 1% for both genders and all races and ethnicities over the 2010-2012 timeframe (Blackwell & Lucas, 2014). Chronic disease has often limited activities of daily living, reduced patients' quality of life, required increased medical management, and potentially led to disability and death (NCCDPHP, 2019). Chronic disease and associated complications contributed significantly to the morbidity and mortality of older Americans (NCCDPHP, 2019).

Advance care planning (ACP) has provided patients with a process for communicating how personal values and beliefs impact current and future health care decisions with both their family and primary care providers (Detering & Silveira, 2018). The Patient Self-Determination Act was enacted in 1990; it required all Medicare-participating health care facilities to provide ACP education and to protect patients' rights to determine their own health care decisions (Kelley, 1995; National Healthcare Decisions Day [NHDD], 2019). In an effort to raise awareness regarding the importance of advance directives, Virginia proclaimed the first Healthcare Decisions Day on April

16, 2006 (Nathan Kottkamp, n.d.). The day after tax-day was specifically selected in response to a prominent Virginian, Benjamin Franklin's belief that "nothing in life is certain but death and taxes" (Nathan Kottkamp, n.d.). National Healthcare Decisions Day has subsequently expanded to all 50 states with support of The Conversation Project through providing free ACP information nationwide (NHDD, 2019). In the United States, Living Wills and Medical Powers of Attorney are the advance directive documents recognized by state law for describing patients' preferences in designating a health care agent (HCA) to make health care decisions on their behalf should they become incapacitated or at end-of-life (Detering & Silveira, 2018).

A data analysis of the national *HealthStyles Survey* found of 7,946 U.S. adults over the age of 18 years old, only 26.3% had reported having an advance directive (Rao, Anderson, Lin, & Laux, 2014). Yadav et al. (2017) found similar results for U.S. adults with chronic disease. After conducting a systematic review involving 795,909 subjects in 150 studies, Yadav et al. (2017) reported the proportion of advance directives completed by U.S. adults with chronic disease was 38.2%, only slightly higher than the percentage completed by healthy U.S. adults, 32.7%, even though chronic disease is frequently associated with increased morbidity and mortality (Dunning, Martin, Orford, & Orellana, 2018; Roper et al., 2001; Yadav et al., 2017).

The CDC (2012) has advocated ACP be conducted at any age or stage in life and may be modified at any time, depending on the patients' health status and life circumstances. As patient participation in health promotion, disease prevention, and most importantly, co-management of chronic diseases has been endorsed by both the CDC

(2012) and the American College of Physicians (ACoP), advance care planning discussions should become an integral part of chronic disease co-management (ACoP, 2015; CDC, 2012). The Institute of Medicine's (IOM) 2014 report, *Dying in America*, also recommended advance care planning discussions occur earlier in patients' lives as an important initiative in respecting patients' autonomy and dignity at their time of death (IOM, 2014).

Despite the recommendations of the ACoP, CDC, and IOM, ACP has primarily been initiated when patients experienced a decline in their health, typically coinciding with initiating palliative care and ultimately hospice care. This delay in providing ACP during the chronic disease process is reflected in the clinical practice guidelines for several of the top chronic diseases with the highest mortality in the United States. The *2013 American College of Cardiology/American Heart Association Heart Failure Guidelines* recommended introducing palliative care for patients with symptomatic, advanced heart failure with a Class I recommendation and Level of Evidence B (Yancey et al., 2013). There was no mention of introducing advance care planning earlier in the heart failure disease progression. The *2018 Report on the Global Strategy for the Diagnosis, Management, and Prevention of COPD* recommended advance directives be introduced at the end-of-life when discussing patients' views on resuscitation and preferred place of death (Global Initiative for Chronic Obstructive Lung Disease, 2018). Even though the *Veterans Administration/Department of Defense Clinical Practice Guideline for the Management of Type 2 Diabetes Mellitus in Primary Care* did advocate for self-management and shared decision-making, the guideline lacked recommendations for any form of ACP or advance directive discussion for diabetics (U.S. Department of Veterans Affairs, Department of Defense, 2017).

The disease trajectory for diabetes is unpredictable and may lead to potentially debilitating complications and premature death (Dunning & Martin, 2017). Currently, over 90% of Type 2 DM patients are managed by their primary care providers (Wexler, 2019). A survey of 1,669 Californians in 2011 indicated 80% of the subjects wanted to talk with their doctor about end-of-life issues, but only 7% of subjects had actually done so (Institute of Healthcare Improvement [IHI], 2014). The lack of ACP discussions in primary care has led to diabetic patients' wishes not being fulfilled as intended and family members experiencing significant distress when attempting to make health care decisions they were unprepared for. Given the current diabetes epidemic and its increased risk of life-threatening complications and premature death, diabetic patients should feel empowered to discuss advance directives with their primary care providers (CDC, 2012).

Most diabetic patients require frequent office visits, often every 3 to 6 months, to evaluate and treat any diabetes-related complications that may develop (Wexler, 2019). These frequent primary care visits provide an excellent opportunity for diabetic patients to discuss not only their current health status, but also inquire about potential disease progression and possible options for care in the future: ACP. U.S. adults have reported they would like to discuss ACP with their primary care providers (PCPs) (IHI, 2014). Musa, Seymour, Narayanasamy, Wada, and Conroy (2015) conducted a survey of 1,823 community-dwelling older adults and found 30% of the respondents were in favor of discussing ACP with their PCPs, but only 17% actually did. The respondents indicated the most important factor for completing an advance directive was being offered the opportunity to discuss ACP in the first place (Musa et al., 2015). Patients appeared to await the PCP to initiate the ACP discussion, which is in contrast with a study conducted by Jackson, Rolnick, Asche, and Heinrich (2009) that found a majority of subjects, 62% of 187 surveyed, felt it was the patients' responsibility to initiate ACP discussions with their PCPs.

The purpose of this interventional study was to determine if providing ACP education to diabetic patients in the primary care setting, earlier in their disease process, improved their readiness to discuss advance directives with their family and PCPs. This study appears to be one of the first in the United States specific to ACP and the diabetic patient population. Several studies have been conducted in Australia and Canada, but none were identified within the United States following an extensive literature search. This study was conducted to provide additional evidence regarding ACP specific to a diabetic patient sample, exploring if diabetic patients were receptive to education on ACP in primary care and as a result reported increased readiness to discuss and complete advance directives.

Goodwin, Kiehl, and Peterson's (2002) Advance Directive Decision-Making Model (ADDMM) served as the theoretical framework for the intervention when providing ACP education (Figure 1). The ADDMM advocated for a holistic approach to ACP discussions, understanding that the discussions involved an active interaction of perceptions between both the researcher and the subject (Goodwin et al., 2002). The goal of the discussion was to improve subjects' perceptions of their health status and power for decision-making by selecting one action over the alternative of doing nothing (Goodwin et al., 2002). In other words, the goal was, after educating subjects about ACP, that they would feel empowered to make an advance directive decision (Goodwin et al., 2002).

Diabetic patients have perceptions of their own health status, which may or may not coincide with the perceptions of their PCPs (Cleary, 2016). Engaging diabetic patients in an interaction, a shared decision-making discussion, of the unpredictable disease trajectory of diabetes, the limits of life-sustaining measures, and the benefits of ACP increased diabetic patients' knowledge and confidence in exercising their right to self-determination. Diabetic patient readiness to discuss and complete advance directives with family and providers was assessed before and after the intervention to determine the impact of education on action. Finally, the interaction between the subject and the researcher was beneficial to both as both were able to achieve mutual goal attainment; the diabetic patient gained confidence in making informed decisions regarding future goals of care (Goodwin et al., 2002).

The research question for this study was among diabetic patients presenting for a primary care office visit: How does receiving ACP education improve their readiness to discuss advance directives compare to their readiness prior to receiving the advance care planning education?

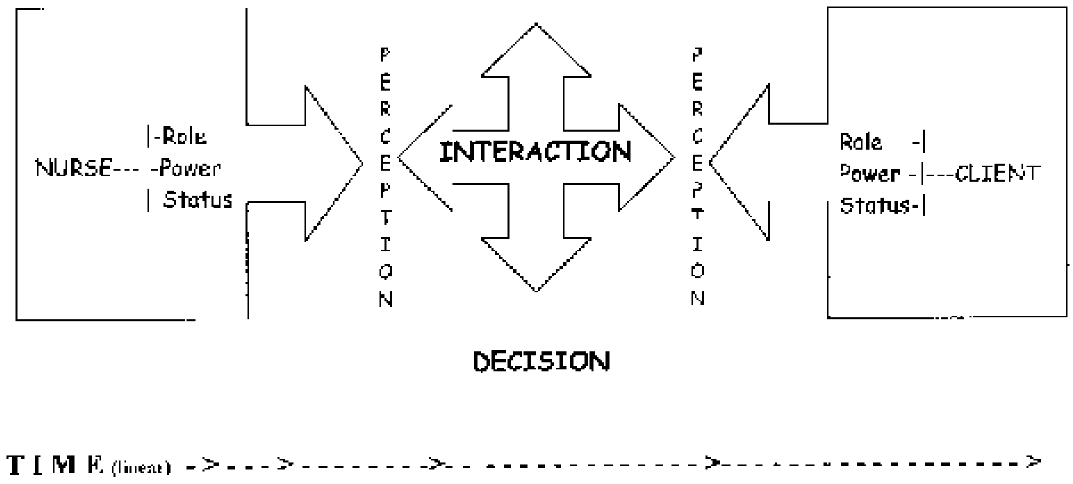

Figure 1. Advance Directive Decision-Making Model. Adapted from "King's Theory as Foundation for an Advance Directive Decision-Making Model," by Z. Goodwin, E. M. Kiehl, and J. Z. Peterson, 2002, *Nurse Science Quarterly, 15,* p. 240.

The hypothesis statements for the research study were as follows. The null hypothesis (H_0) postulated providing education on advance care planning to diabetic patients during primary care office visits does not improve their readiness to discuss advance directives. The alternative hypothesis (H_1) postulated providing education on advance care planning to diabetic patients during primary care office visits improves their readiness to discuss advance directives.

The variable readiness was developed from the concept of stages of change classified within behavioral change theory (Shaw, Hewson, Hogan, Bouchal, & Simon, 2017). The stages of change are precontemplation, contemplation, planning, action, and maintenance (Shaw et al., 2017). Behavior change theory has identified readiness as one of four key factors patients need in order to change their behavior; the other three factors are knowledge, contemplation, and self-efficacy (Sudore et al., 2013). Fried, Bullock, Iannone, and O’Leary (2009) identified individuals who recognized readiness is necessary to move to action. Previous studies identified patients and family members associated readiness with a need for information to guide decision-making (Shaw et al., 2017). Understanding patients and families are at different stages of readiness, providing education on ACP may be the activity needed to move patients further along the ACP process.

In summary, education-based interventions have been shown to increase knowledge, and influence ACP readiness and behavior, which has resulted in increased advance directive completions (Kermel-Schiffman & Werner, 2017; Sudore et al., 2014). Knowing diabetes is associated with an increased number of complications and possible premature death, diabetic patients should feel empowered to exercise their right to self-determination and discuss advance directives with their families and PCPs earlier in their disease process, when still healthy and capable of making advance directive decisions for themselves.

Chapter 2: Integrated Review of Literature

A computer-based literature search was conducted using several bibliographic databases including Agency for Healthcare Research and Quality, Cumulative Index to Nursing and Allied Health Literature, Cochrane Database of Systematic Reviews, Evidence-Based Medicine, National Guideline Clearinghouse, OVID, PubMed/MEDLINE, Trip, Google Scholar, and grey literature from inception to November 2019. Keywords used were diabetes*, diabetes management*, advance care planning*, advance directives*, patient education*, Five Wishes®, advance care planning readiness*, and primary care*. Truncation of keywords with an asterisk (*) was also used to locate additional letters beyond the root word when conducting the literature search. Ancestry or hand searches were also conducted of the reference lists of selected articles to locate subsequent articles missed by the initial search. Duplicate and nonrelated papers were excluded following the first search.

Initially, titles were searched using keywords and Booleans “or” then “and.” The resulting abstracts were screened for inclusion and exclusion. Inclusion criteria were (a) adult outpatient diabetic populations, (b) adult chronic disease populations, (c) advance care planning or advance directive, (d) advance care planning readiness, (e) primary care, (f) published in English from inception to 2019, and (g) available abstract or full text. Studies that were excluded were not available in English, or referenced inpatients, pediatric patients, or psychiatric patients.

The literature search resulted in just over 700 articles and studies involving diabetes, chronic disease, advance care planning or advance directives, Five Wishes®, and advance care planning readiness as keywords, subject headings, or titles. Sixty-four articles and studies met the inclusion criteria from the electronic search. The abstracts of the 64 articles and studies were reviewed, resulting in an additional 24 studies being excluded. The remaining 40 articles and studies were further reviewed for alignment with the inclusion criteria, resulting in narrowing the number of higher-level-of-evidence studies to 19 (Figure 2).

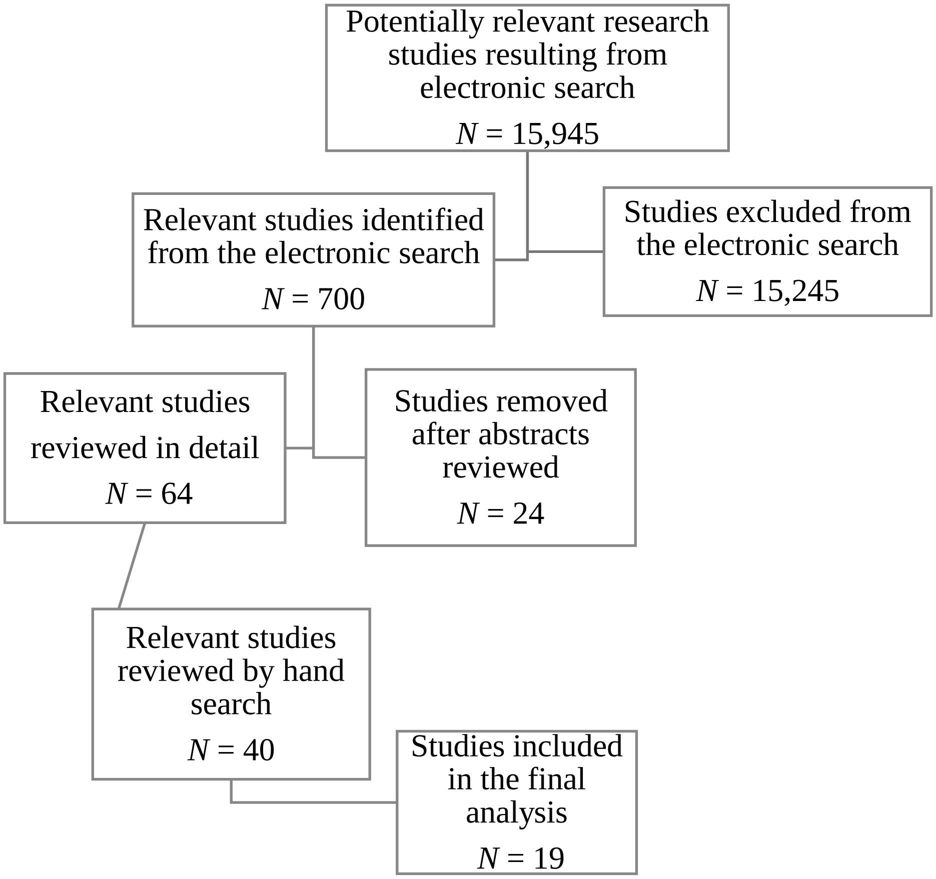

Figure 2. Literature search results. Adapted from “Strategies used to facilitate the discussion of advance care planning with older adults in primary care settings: A literature review” by G. R. Solis, B. M. Mancera, & M. J. Shen, 2018, *Journal of the American Association of Nurse Practitioners 30*(5), p. 273. Copyright 2018 by the American Association of Nurse Practitioners.

The higher-level-of-evidence studies included three systematic reviews, two randomized control trials, one nonrandomized control trial, two systematic reviews of descriptive studies, seven qualitative or descriptive studies, and four consensus opinions being clinical practice guidelines. Additional journal articles were retained to assist with identifying the best evidence-based practice recommendations for increasing advance care planning readiness among diabetic patient populations and a validated advance care planning readiness measurement instrument for this study.

A total of nineteen studies (N = 19) were selected for this literature review on improving advance care planning (ACP) readiness amongst diabetic patients. Almost all of the 19 studies included ACP in their title, two of the studies specifically involved diabetic patient populations, four studies provided patients' perspectives on and experiences with ACP, three studies discussed ACP knowledge, two studies focused on ACP readiness, and three promoted ACP discussions in primary care. The cross-section of studies for review were chosen to provide a broad overview of current evidence regarding ACP specific to patients diagnosed with diabetes.

Role of Advance Care Planning in Diabetes Management

The current research regarding ACP within the diabetes (DM) patient population is limited. A majority of the articles published in peer-reviewed journals consisted of ACP and DM involved recommendations for earlier introductions of palliative care and end-of-life (EOL) discussions. Dunning and Martin (2017) were strong advocates for a proactive approach to EOL and advocated for earlier use of palliative care, which encompassed ACP discussions as an important part in providing holistic care to diabetics.

The disease trajectory of DM is complex and unpredictable with patients often experiencing unexpected complications, resulting in further functional decline and ultimately death (Dunning & Martin, 2017). Death is very difficult to predict, making it challenging to identify the best time to introduce palliative care with ACP and EOL discussions (Dunning & Martin, 2017). Delays in discussing ACP led to missed opportunities for diabetic patients to express their values, beliefs, and thoughts regarding future treatment to their families and providers.

Dunning, Duggan, and Savage (2016) proposed one way to address the uncertainty regarding the best time to introduce ACP in the DM patient population is to use EOL prognostic tools. Several tools, the Gold Framework and Karnofsky Performance Scale, have been developed for prognosing when patients may be approaching EOL. These tools may assist diabetic patients, families, and providers in determining the best time to discuss palliative care with ACP and EOL (Dunning et al., 2016). The Gold Standard Framework criteria for prognosis includes, but is not limited to, (a) weight loss of greater than 10% in the past 6 months, (b) a serum albumin level less than 25 grams per liter, and (c) an increased need for support to complete activities of daily living (Dunning et al., 2016; Glaudemans, van Charante, & Willems, 2015). Cleary (2016) recommended palliative care with ACP be introduced when the Karnofsky score is 50% or less. Dunning and Martin (2017) expanded on this concept of the best time to introduce palliative care with ACP and EOL discussions with diabetics by developing a list of DM-specific triggers. The DM-specific triggers include (a) duration of DM diagnosis greater than 10 to 15 years; (b) glycated hemoglobin (HgbA1c) consistently greater than 7%; (c) glucose variability, specifically hypoglycemia; and (d) being diagnosed with CVD, ESRD, lower extremity disease, and frailty (Dunning & Martin, 2018). Despite these recommendations and prognostic tools, diabetic patients, families, and providers have not been engaging in palliative care with ACP and EOL discussions.

Factors Contributing to the Lack of Advance Care Planning Amongst Diabetics

Besides providers frequently expressing challenges with knowing what to say and when, primary care providers (PCPs) have expressed a hesitancy to engage in ACP due to a lack of skills or training on how best to facilitate these potentially emotional discussions (Butler, Ratner, McCreedy, Shippee, & Kane, 2014; Dunning & Martin, 2017). Providers have also reported patients' lack of understanding of their disease process and the limits of life-saving measures as two more barriers to engaging in ACP discussions (Howard et al., 2018; Scholten et al., 2018).

The barriers to discussing ACP were not only found among providers but were also reported by diabetic patients as well. Savage, Duggan, Dunning, and Martin (2012) completed a qualitative study of 14 diabetic patients and found of the 14 subjects interviewed, only one had completed an advance directive, a 7% advance directive completion rate among this diabetic sample. Savage et al. (2012) and Dunning, Martin, Orford, and Orellana (2017) reported the diabetic subjects were interested in discussing ACP with their PCPs, but had not because their PCPs had not asked them about their plans for future care. Several of the diabetic subjects added that if they had been asked about ACP by their PCPs, they were fearful of upsetting their providers (Dunning, et al., 2017; Savage et al., 2012). When Savage et al. (2012) asked the diabetic subjects why they had not completed an advance directive, several subjects stated they were not aware of advance directives, and the remaining diabetic subjects stated they had not given any thought to completing an advance directive as part of their diabetes management (Savage et al., 2012). This is in line with the findings reported by Hash, Bodnar-Deren, Leventhal, and Leventhal (2018), who conducted a survey of 305 older adult subjects in a New Jersey EOL study. Hash et al. (2018) found diabetic subjects were less likely to complete advance directives due to diabetics having a lower self-perceived disease burden, meaning fewer physical and mental symptoms, as compared to patients with other chronic diseases such cancer or COPD.

Recommendations for Improving Diabetics' Readiness for Advance Care Planning

Zwakman et al. (2018) conducted a systematic review of 20 articles exploring the ACP experiences of patients with life-threatening or life-limiting illness, including DM, and found patients reported a reluctance to engage in ACP due to a fear of discussing their own death or being a burden to their families. Readiness was one of three main themes identified as a recurrent aspect of these patients' experiences with ACP (Zwakman et al., 2018). Patient readiness to engage in discussions was found to be a key component to the success of ACP among patients with chronic disease, and more importantly, the researchers found readiness can be promoted by participating in the ACP process itself (Zwakman et al., 2018). In other words, ACP readiness may be improved by providing patients with information on ACP and advance directives.

Fried et al. (2009) conducted a qualitative cross-sectional study involving 63 community dwellers over the age of 65 and 30 caregivers with experience as HCAs. The aim of the study was to explore whether models of heath behavior change would assist in developing effective interventions to improve patients' ACP readiness (Fried et al., 2009). Fried et al. (2009) identified four themes that assist in developing effective interventions to improve patient readiness for ACP. The four themes were that subjects (a) were often in different stages of ACP readiness, (b) were aware of the benefits and barriers to ACP, (c) used various processes to progress through stages of change, and (d) were influenced by prior experiences with health care decision-making for loved ones (Fried et al., 2009). The introduction of ACP as a routine part of chronic disease management and having patients reflect on prior health care decision-making experiences for a loved one were identified as the top two motivators for improving ACP readiness (Fried et al., 2009). Shaw et al. (2017) conducted a descriptive study of 27 subjects to characterize ACP readiness among assisted living residents, families, and providers. Shaw et al. (2017) also found subjects' previous experiences with EOL decisions for a loved one and personally experiencing a prior health crisis greatly influenced their readiness to engage in ACP.

While advocating for integrating palliative care with ACP into primary care for patients with chronic disease, Cleary (2016) stated patient readiness to engage in ACP can be adversely impacted if the patient's perception of his or her own health status does not correlate with the patient's actual state of health, as determined by the individual's PCP. Patients often adapt to their chronic disease and their associated declining level of function, and as a result, often lose perspective of their true deficits and susceptibility to potentially life-threatening complications (Cleary, 2016). This loss of perspective, coupled with a lack of education regarding their prognosis and possible options for future treatment, result in a false sense of security, leading them to believe that emergent, life-saving measures will fully restore their health (Cleary, 2016; Messinger-Rapport, Baum, & Smith, 2009).

Kermel-Schiffman and Werner (2017) conducted a systematic review of 37 studies exploring ACP knowledge and found a majority of the studies indicated education-based interventions improved patient knowledge and readiness to engage in ACP (Nouri et al., 2019). Nouri et al. (2019) conducted a cross-sectional design study of 1,400 patients and concluded that providing ACP with easy-to-understand educational materials is one of the most important factors in improving ACP readiness: even more important than a patient's prior experience with ACP.

Advance Care Planning Educational Tool: Five Wishes®

One such easy-to-understand ACP educational tool is Five Wishes®. Five Wishes® was first created by Jim Towney following his work with Mother Teresa in caring for the sick in the 1990s (Aging with Dignity, 2019). The ACP document was developed in collaboration with the American Bar Association with support from the Robert Wood Johnson Foundation and was first published in 1998 (Aging with Dignity, 2019). Five Wishes® is considered a legal ACP document for 42 states within the United States, including Virginia (Aging with Dignity, 2019). This ACP document has been the first advance directive to address not only future health care decisions, but also the emotional and spiritual issues that often accompany health crises (Aging with Dignity, 2019).

Butler et al. (2014) conducted an interview with seven ACP informants, providers, and attorneys, and reviewed 16 studies exploring the current ACP decision aids or tools available for use. Butler et al. (2014) described Five Wishes® as an ACP decision tool primarily targeted for healthy adults. The document was written in everyday language so patients can easily understand the content and use the document as a plan for future care prior to experiencing an unexpected health crisis or continued decline at the EOL (Aging with Dignity, 2019). Five Wishes® was written at an eighth-grade reading level, which is also the average reading level of U.S. adults (Aging with Dignity, 2019; Nouri et al., 2019; Wickersham, Gowin, Deen, & Nagykaldi, 2019). The document is currently available in 27 languages (Aging with Dignity, 2019).

According to the International Patient Decision Aids Standards criteria, Five Wishes® was found to provide a low level of structured approach and education with a medium level of how decisions were communicated, while MyDirectives and PREPARE, additional ACP decision aids available for use, were found to provide a medium level of structure approach and education with a high level of decision communication (Butler et al., 2014). Both MyDirectives and PREPARE were computer-based ACP decision aids that required Web-based tools, which often created barriers for ACP completion for vulnerable populations (Butler et al., 2014). Five Wishes® is available online and also as a written packet readily available for use (Agency on Aging, 2019).

Wichersham et al. (2019) conducted a pair-matched cluster randomized study in six primary care practices in which 2,748 patient encounters were evaluated comparing Five Wishes® with the state of Oklahoma's advanced directive form. The study found both providers and patients preferred Five Wishes® over Oklahoma's advance directive form (Wichersham et al., 2019). Providers reported Five Wishes® was better accepted by the patients and proved to be easily accessible to patients, with written documents available in the office and supplemental information available online (Wichersham et al., 2019). Patients stated Five Wishes® was easy to follow, effectively captured their wishes, and provided an opportunity to document their specific care priorities (Wichersham et al., 2019).

Atherton (2019) utilized Five Wishes® in a 16-week trial designed to increase the number of advance directives completed in a Northern Arizona practice. The practice's advance directive completion rate jumped from 0.8% to 26.2%, a 25.4% increase in 16 weeks with the use of Five Wishes® (Atherton, 2019). Five Wishes® is also the educational ACP document recently chosen, November 1, 2019, for use by Riverside Health System, the governing body of the clinical site to be used for this study (Figure 1; Appendix B).

Evidence-Based Best Practice Recommendations

Butler et al. (2014) advocated that when approaching chronic disease patients, such as those with diabetes, the ACP discussion should include information regarding the patient's prognosis and the efficacy of various life-sustaining treatments including both risks and benefits. Messinger-Rapport et al. (2009) reported patients often overestimate the successful outcomes of life-sustaining measures. When conducting discussions regarding ACP, Messinger-Rapport et al. (2009) agreed that providing a clear picture of the patient's prognosis with the risks and benefits of life-sustaining treatment should ensure patients were aware of the potential outcomes of cardiopulmonary resuscitation (CPR) given their medical condition. Patients often overestimate CPR survival rates by 60.4% (Kaldjian et al., 2009). Meaney et al. (2010) conducted a retrospective chart review of 51,919 patients between April 1999 and July 2005 and found between 7% and 37% of post-cardiac arrest patients survived to hospital discharge, and of those who survived, 14% had poor neurological outcomes (Peberdy et al., 2003). Cleary (2016) and Messinger-Rapport et al. (2009) proceeded to recommend integrating these ACP discussions into primary care in a stepwise approach. A stepwise approach improved ACP readiness by assisting patients and families in assimilating the information provided, focusing on a values-based, goal-oriented plan for further care in support of making sound decisions and naming a HCA (Messinger-Rapport et al., 2009).

Advances in health care have led to extended life expectancy, but for those with chronic disease, that means patients are frequently living longer with greater disease burden and functional decline (Cleary, 2016). Common among chronic diseases, such as DM, CVD, COPD, was a disease progression that remained relatively stable, but also included multiple serious complications or exacerbations, which resulted in sudden unexpected declines in health status and possible death (Mullick, 2013; Nishikawa et al., 2018). Nishikawa et al. (2018) stated this unpredictable morbidity and mortality was the reason for not waiting to discuss ACP during patient exacerbations, but discuss ACP earlier in the disease process when the patient was healthy and capable of making these decisions. Detering, Hancock, Reade, and Silvester (2010) reported by engaging in ACP earlier, patients and caregivers experienced less stress, improved quality of life, increased use of palliative care, and decreased subsequent hospitalizations.

Limited Number of Research Studies Specific to the Diabetic Patient Population

The major gap in the literature specific to ACP within the diabetic patient population was the lack of studies on the topic. The literature review led to multiple studies involving ACP and various other chronic diseases including congenital heart disease, heart failure, and ESRD, but only two were identified specific to ACP and diabetes. There were a number of recent articles found in peer-reviewed journals written by several of the same researchers following interviews of diabetic patients in Australia. The focus of the interviews conducted by Dunning et al. (2018) was exploring the lack of palliative care with ACP and EOL discussions occurring in DM care, with the interest of developing guidelines for managing diabetes at EOL. Throughout these articles and the single qualitative study conducted by Savage et al. (2012), ACP was not considered as an initial or independent step in the process for respecting a patient's right to autonomy and dignity at the time of death, but as a subsequent component of palliative care with ACP and EOL discussions when the diabetic patient's health status was declining (Dunning, 2018; Dunning, Duggan, & Savage, 2016; Dunning & Martin, 2018). Several of the articles acknowledged the unknown disease trajectory diabetic patients face and proceeded to recommend the use of prognostic tools to determine the best time to discuss palliative care with ACP and EOL (Dunning, 2018; Dunning et al., 2016; Dunning & Martin, 2018). Again, all of the articles paired palliative care with ACP, to be introduced later in the DM disease progression when approaching EOL (Dunning, 2018; Dunning et al., 2016; Dunning & Martin, 2018).

A second study specific to ACP and diabetic patients was conducted in Canada in 1998. Toth, Gill, Godkin, and Lee (1998) conducted a survey of 27 insulin-dependent diabetics (IDDM) to better understand their knowledge, attitudes, and behaviors regarding advance directives. The mean age of respondents was 49 and all of the respondents felt it was extremely important that they have a say in the type of health care they received (Toth et al., 1998). A majority of respondents, 89%, reported the best time to discuss ACP was when they were well, during their routine DM management visits (Toth et al., 1998). This was in line with the ACoP's, CDC's, and IOM's recommendations for incorporating ACP into primary care (ACoP, 2015; CDC, 2012; IOM, 2014).

Lack of Diabetic Practice Guidelines Supporting Early Advance Care Planning

As a result of the limited studies specifically involving ACP and the diabetic patient population, the literature review was broadened to include the current clinical practice guidelines for the management of DM. As mentioned earlier in the introduction, multiple clinical practice guidelines for the chronic diseases with the highest mortality rates in the United States did not mention ACP as a part of long-term care of these deadly diseases. The American Diabetes Association (ADA) *Standards of Medical Care in Diabetes – 2019* contained a chapter on older adults that included a section on EOL, but again, there was no recommendation or mention of ACP in the provision of diabetic care, even among older adults (2019). Upon further review of the ADA website, a page was located titled “Planning for Your Later Years” that included guidance on EOL planning, which included (a) formulating an estate plan, (b) drafting a letter of instruction, and (c) preplanning of funeral arrangements; however, there was no mention of advocating DM patients discuss ACP early in their disease process with their family or PCPs when healthy and able to discuss future goals of care (ADA, n.d.).

Summary of Gap in Knowledge

In summary, the number of research studies regarding ACP and DM was very limited; only two studies were identified, a qualitative study of 14 diabetic subjects in Australia and a survey of 27 IDDM patients in Canada. The qualitative study found only one subject or 7% of the diabetic subjects had completed an advance directive (Savage et al., 2012). The primary reasons reported for not completing the advance directive were a lack of awareness regarding ACP, and for those aware of ACP, a lack of a sense of necessity to complete an advance directive with regards to their DM diagnosis (Savage et al., 2012). In the second study specific to ACP and DM, the survey of 27 IDDM subjects found a majority, 89%, of the subjects felt ACP should be discussed during routine office visits when healthy and able to make decisions for themselves (Toth et al., 1998). Given the limited number of studies specific to ACP and DM, the literature review was again expanded to include research studies involving ACP and chronic diseases, which provided additional information regarding recommendations for improving ACP readiness among chronic disease patients.

This Study's Contribution to Current Knowledge

The research indicated ACP was often paired with palliative care and EOL, and as a result, continued to often be delayed; it was only introduced when a patient's condition has declined significantly or when the patient has become symptomatic and approaching EOL within the year. This delay in introducing ACP until the final year of life has resulted in patients not receiving the care they intended when they experienced an abrupt change in health status for which they were not prepared.

The latest statistics for diabetes in the state of Virginia indicated the prevalence of DM is higher than that of the United States. Diabetes diagnoses have increased 3%, from 7.4% in 2006 to 10.4% in 2016 (CDC, United States Diabetes Surveillance System [USDSS], Division of Diabetes Translation, 2016). The percentage of patients diagnosed with DM in Newport News, Virginia, the site of the research study, was higher than that of both the state of Virginia and the United States: 10.3% in 2006 increased to 13.8% in 2016 (CDC, USDSS, 2016). These statistics confirmed the diabetes epidemic included the local residents of Newport News, VA. A doctoral-prepared Family Nurse Practitioner (DNP FNP) at the study site has seen approximately 20 to 25 patients daily with almost one-fifth to one-quarter of patients seen were diabetics. Multiple ACP opportunities were identified while completing 180 hours of clinical practicum over a 6-month timeframe in 2018 and 2019. A limited number of ACP discussions were observed during that time, most of which were at the request of the patient, revealing more than 145 potential missed opportunities.

These missed opportunities have left many diabetic patients vulnerable to receiving health care they never intended and not according to their wishes. According to Narang et al. (2015), the lack of an advance directive has led to unnecessary distress for both patients and caregivers, has disregarded patients' values and beliefs, and threatened patients' autonomy and dignity at the end of life. If providers do not engage in ACP discussions, diabetic patients should feel empowered to initiate the ACP discussion on their own behalf.

The aim of this research study was to explore whether providing a sample of diabetic patients in Newport News, VA with ACP education using the easy-to-understand Five Wishes® document will improve patients' readiness to initiate advance directive discussions with their family and providers. This study supported expanding on the current trend of engaging diabetic patients in co-managing their disease with their PCPs to include discussions of ACP. This study confirmed informing diabetic patients about their possible future disease progression, including complications and premature death, and educating them about ACP and their right to self-determine future goals of care, increased their readiness to discuss ACP earlier in their disease process.

Chapter 3: Methods

This study was conducted as a research study using the scientific, which explored whether providing education with the Five Wishes$^{®}$ advance directive document to a diabetic patient population in Newport News, VA would improve their readiness to discuss advance care planning (ACP). A pretest-posttest design was used for this interventional study. This study design was chosen to identify a change in behavior: increased readiness on the part of diabetic patients to discuss advance directives in primary care (Polit & Beck, 2012). A convenience sample was recruited for this study. The primary outcome variable for the study, ACP readiness, was measured using the Advance Care Planning Engagement Survey, 4-item version (ACP ES4). The secondary outcome variables that were obtained during the post-intervention follow-up call 2 weeks after the intervention were whether the subject (a) completed an ACP discussion with a family member, (b) designated a HCA, and (c) completed an advance directive.

Project Sample

The outpatient setting for this study was Riverside Bruton Avenue Family Practice, located in Newport News, VA. This family practice office is part of Riverside Health System, a private non-profit corporation managed by a Board of Directors (Riverside, n.d.). Riverside Health System's mission is "To care for others as we care for those we love" (Riverside, n.d.). Two physicians and one Doctor of Nursing Practice Family Nurse Practitioner (DNP FNP) provided comprehensive medical services for the entire family at the Bruton Avenue location (Riverside, 2018).

Both inclusion and exclusion criteria were applied when selecting eligible subjects for the study. The inclusion criteria were all English-speaking, outpatients, over the age of 18 who have been diagnosed with DM, do not have an advance directive, and are able to provide consent. The exclusion criteria consisted of non-English speaking patients, pediatric patients, patients currently receiving palliative care or hospice care, patients who have already completed an advance directive, and patients experiencing any of the following: (a) acute episode of illness, (b) cognitive impairment, (c) blindness, (d) deafness, (e) active drug or alcohol abuse within past 3 months, or (f) lack a telephone.

Institutional Review Board (IRB) approval was obtained from both Radford University and Riverside Health System. Riverside Health System granted IRB approval for exemption in compliance with 45 CFR 46, Category 2, Category 3 (B) on January 16, 2020. An IRB Authorization Agreement between Radford University and Riverside Health System was completed and signed February 14, 2020. Radford University's IRB granted approval February 14, 2020 with reliance on Riverside Health System's IRB for the initial review and oversight of the collaborative research.

The informed consent process was the first method of protection for the patients who considered participating in the study. During the patient's routine office visit, the provider informed the patient of the study being conducted and if the patient expressed interest in participating the provider introduced the patient to the researcher. The researcher provided an overview of the study and a copy of the Informed Consent for review (Figure A1). Next, the researcher educated the subject regarding the content of the Informed Consent form, the processes in place to protect subject confidentiality, the information required of the subject, the subject's responsibilities, and the time required to participate in the study. The researcher also informed the subject that the risk associated with participating in the study was minimal, no more than what the individual experienced in daily life and that he or she could withdraw from the study at any time. The researcher addressed any questions the subject had prior to the subject's signing the Informed Consent form. Once all the subject's questions had been answered, the subject decided whether to sign the Informed Consent form or not. If the patient signed the Informed Consent form and agreed to enter the study, the researcher provided the subject with a copy of the signed consent form.

Anonymity of the subjects was the second method for protecting the subjects during the study and was immediately achieved upon entry into the study as subjects were assigned randomly generated numerical identifiers after signing the Informed Consent form and prior to completing any surveys. The researcher maintained the subject directory in a password-protected file on a password-protected personal laptop.

Finally, the confidentiality and privacy of the study subjects was initiated upon entry into the study. The study was conducted in a private room within the family practice site.

The anticipated risks with participating in the study were minimal, no more than what the subject would have experienced in everyday life. If a subject had reported an adverse outcome from participating in the study, the subject would have been referred to one of the providers within the Family Practice office for further evaluation and treatment and if needed, provided a list of local counselors in the area for further treatment. None of the subjects reported an adverse outcome. Finally, any accidental exposure of survey responses would not have placed the subjects at risk or resulted in psychological, physical, or financial harm as the surveys were deidentified.

Instruments

Sudore et al.'s (2017) ACP ES4 was utilized for this study (Figure A2). The initial 82-item Likert-type survey instrument was first developed in 2013 and has been previously validated in multiple studies (Howard et al., 2016; Sudore et al., 2013). Sudore et al. (2017) recently conducted a study of 501 subjects assessing the internal consistency and construct validity of shorter versions: 55-, 34-, 15-, 9-, and 4-item surveys. Sudore et al. (2017) concluded the shorter versions of the ACP ES were valid and internally consistent, Cronbach's alpha ranging from 0.84 to 0.97. The 9- and 4-item surveys were recommended as appropriate for use for quality improvement initiatives in clinical studies and for research studies with limited resources, such as this study (Sudore et al, 2017).

The ACP ES4 is comprised of two main sections: process measures and action measures (Sudore et al., 2013). The 4-item version of this survey was used as the pre- and post-intervention surveys for this study, which was administered initially in person, on paper, and then again verbally during a follow-up call 2 weeks later. The survey, pretest and posttest, consisted of four questions specific to the process measure of readiness (Sudore et al., 2013). The concept of readiness for this study evolved from the behavior change theory (Fried et al., 2009; Sudore et al., 2013). Readiness has been recognized as one of four key factors patients need in order to change their behavior; the other three factors are knowledge, contemplation, and self-efficacy (Sudore et al., 2013). The four questions asked were how ready the subjects are to (a) talk with their HCA about wishes for future care, (b) talk with their provider about wishes for future care, (c) sign official papers to put their wishes in writing, and (d) sign official papers naming a HCA to make future care decisions on their behalf should they be unable to (Sudore et al., 2017). Each of the four readiness questions were accompanied by a list of available responses the subjects must choose from. The available responses, (a) not at all, (b) a little, (c) somewhat, (d) fairly, and (e) extremely, are associated with a 5-point Likert scale with “not at all” assigned one point to “extremely” assigned five points (Sudore et al., 2013). A subject’s level of readiness for each question was scored according to the subject’s response and the Likert scale point value assigned to that response (Sudore et al., 2013). The subjects’ responses provided an ordinal level of measurement. Level of readiness scores were calculated for each of the four questions and then an overall level of readiness score was calculated by averaging the subjects’ responses to all four questions before and after the educational intervention (Sudore et al., 2013). Higher scores indicated the subjects had an increased level of readiness to discuss ACP with family and PCPs as well as complete an advance directive.

In addition to the ACP ES4, a demographic questionnaire and follow-up survey were completed. The demographic questionnaire was administered at the beginning of the study to provide the subjects’ age, gender, self-reported race, ethnicity, and social and health status (Figure A3). In response to the literature review and evidence-based best practice recommendations, additional questions were added to the demographic questionnaire to capture diabetes-specific information about the subjects, including the type of diabetes the subjects had, the number of years they had been diagnosed with diabetes, and their perception of their current health status (Butler et al., 2014; Cleary, 2016). The last two questions on the questionnaire explored the subjects' prior ACP experiences with either having had a personal health crisis that impacted their ability to make medical decisions for themselves or with having to act as a HCA on behalf of a loved one and how that made them feel (Freid et al., 2009; Shaw et al., 2017). The demographic questionnaire was conducted in person, on paper, and provided a nominal level of measurement.

The follow-up questionnaire identified if any of the subjects exhibited increased ACP readiness that resulted in a change in ACP behavior by reporting they discussed advance directives with a family member, named a HCA, and or completed an advance directive (Figure A4). Each of the three follow-up questions were accompanied by a list of available responses the participants must choose from. The available responses were (a) yes, (b) no, and (c) plan to within 3 months. The responses were then tallied to determine if the subjects experienced an improvement in ACP readiness as a result of the education received and advanced further along the ACP process to completing an advance directive. The follow-up questionnaire was completed verbally on a phone call 2 weeks after the intervention and it provided a nominal level of measurement.

There were several possible external influences that may have affected the subject's readiness to discuss ACP. Fried et al. (2009) and Shaw et al. (2017) both identified a subject's prior experiences with making EOL health care decisions for loved ones as well as personally experiencing a prior health crisis as possibly affecting a subject's readiness to discuss ACP. A measure to address or control these influences was to initiate the ACP discussion with questions regarding the subjects' prior experiences with ACP and health care crises (Fried et al., 2009). In addition, subjects may have been influenced by a sense of obligation to please their provider from the family practice office. A measure to address this behavior was to ask the providers to introduce the study objectively and ensure patients were not being pressured to participate in the study.

Procedure

Patients diagnosed with diabetes who presented to Bruton Avenue Family Practice for a routine office visit with the providers received an introductory letter and were informed a research study was being conducted in the office and asked if they would like to meet with the researcher to learn more (Figure A5). The researcher, a DNP FNP student at Radford University, determined if the patient was eligible for the study, and if determined eligible, the patient received information regarding the study and informed consent process. If the patient chose to participate in the study and signed the Informed Consent form, a questionnaire was provided capturing the subject's demographic characteristics as well as prior experiences with ACP or personal health crisis when unable to make health care decisions for him or herself. Then pretest and posttest intervention surveys were administered that measured the differences in the diabetic subject's ACP readiness before and after receiving education on diabetes disease progression and the Five Wishes® advance directive form.

The protocol was conducted in three phases. Phase I, the pre-intervention phase, involved preparing all the necessary forms for the study, obtaining IRB approval, securing the office space for the study, and educating the office staff regarding the study. Diabetic patients who presented to the family practice for an office visit were provided an introductory letter. The provider then completed the disease management portion of the visit and informed the patient that there was a research study being conducted in the office. The provider asked if the patient would be interested in meeting with the researcher to learn more about the study and possibly participate. During Phase II, the intervention phase, the patient met with the researcher. If the patient met the inclusion criteria for the study, the researcher proceeded to inform the patient about the study and the informed consent process. If the patient consented to participate, he or she was assigned a randomly generated numerical identifier and given the demographic questionnaire and pre-intervention survey to complete prior to receiving the educational intervention. In Phase III, the post-intervention phase, the subject was called 2 weeks after receiving the intervention and completed the same readiness survey, post-intervention, and a follow-up questionnaire verbally with the researcher.

During the pre-intervention phase, all the necessary forms for the study were created and obtained including an Informed Consent form and a demographic and follow-up call questionnaire, and permissions to use both Sudore et al.'s (2017) ACP ES4 and the Five Wishes® booklet were obtained. IRB approval was obtained from both Riverside Health System and Radford University. Key stakeholder support was secured with the office practice manager and the providers at Bruton Avenue Family Practice.

Once the study began, diabetic patients who presented to the family practice office were given an introductory letter regarding ACP at check-in. The providers completed the patient's interview and exam and then informed the patient that there was a research study taking place in the office. The providers asked the patient if they were interested in meeting with the researcher to learn more about the study. If the patient voiced interest, the provider introduced the patient to the researcher.

The intervention phase began once the patient met with the researcher who screened the patient for eligibility and provided the patient with an overview of the study, the subject's responsibilities, and the informed consent process with a copy of the Informed Consent, which the patient reviewed. If the patient chose to participate in the study and signed the consent form, he or she became a subject and was assigned a numerical identifier and administered a demographics questionnaire followed by the pre-intervention survey. The pre-intervention survey, ACP ES4, was a well-validated instrument for measuring ACP readiness. After the subject completed the pre-intervention survey, the researcher collected and secured the deidentified questionnaire and pre-intervention survey.

The researcher reviewed the subject's responses and then facilitated an organized ACP discussion exploring the subject's current understanding of his or her diabetic disease and possible future disease progression. The researcher asked the subject, "Tell me if you have any plans in place should you have a health crisis." The researcher informed the subject regarding diabetes being a chronic, progressive disease that may lead to disability, individuals no longer being able to care for themselves, or even a health crisis and not being able to make health care decisions for themselves. The researcher informed the subject of the low number of patients who fully recover from life-saving measures and then proceeded to use the Five Wishes® document to discuss options for future care if needed. The approach was conversational in tone with the theme being to hope for the best, but also plan for the rest (Messinger-Rapport, 2009). The researcher addressed any questions or concerns raised by the subject and reminded the subject to expect a follow-up call within 2 weeks.

Two weeks after the intervention, the subjects were called to complete the same ACP readiness measurement tool, the ACP ES4. The subject's identity was verified by asking the subject to provide the name of the university providing oversight of the study, Radford University. Finally, three additional questions were asked of the subjects, inquiring if they had (a) discussed advance directives with their loved ones, (b) chosen a health care agent, and (c) completed an advance directive.The researcher entered the subject's responses in the password-protected data file on the researcher's personal password-protected laptop. The study ended after the follow-up call was completed.

Data Management

The study was conducted in a private room within the family practice site. The demographic questionnaire and pre-intervention surveys were deidentified as the subjects were assigned numerical identifiers. After the subject completed the questionnaire and survey, the researcher secured them in a combination-locked file box, and once the responses were entered into a password-protected file on the password-protected laptop, the surveys were shredded. The post-intervention follow-up call was conducted in a private room and the identity of the subject was verified at the beginning of the call by having the subject provide the name of the university supervising the study, Radford University.

The data will be maintained for a total of 3 years following the end of the study and then deleted. Access to the study data will only be available to the researcher and the Radford University School of Nursing Faculty assigned to this study's DNP Project Committee upon request.

Data Analysis

The Statistical Package for the Social Sciences version 24.0 was used to analyze the data collected from the demographic and follow-up questionnaires and pretest and posttests. The initial step was to describe the sample characteristics followed by testing the hypothesis statements proposed for this study regarding whether or not providing ACP education to diabetic patients increased their readiness to discuss advance directives. The level of significance proposed for this study was $\alpha = 0.5$ in an effort to minimize the probability of rejecting the null hypothesis, that ACP education does not improve ACP readiness, if true (Polit, 2010).

The data was reviewed and cleaned as follows. The amount of missing data ranged from 1% to 7%. The pattern of missingness was missing at random (MAR) (Polit, 2010). The MAR may have been in direct relation to the outbreak of the coronavirus (COVID-19) pandemic on the Virginia Peninsula March 16, 2020 (Polit, 2010). The deletion method chosen to address the missing values was listwise deletion (Polit, 2010). Cases with one or more missing values were deleted from the analysis. Outliers identified as a result of frequency distribution analysis were examined further to assist in determining the outlier's impact on the data to determine if a contributing relationship did exist; if not, the outlier was deleted from the data analysis (Polit, 2010).

The parametric test chosen to analyze the data was a paired *t* test to compare the mean ACP readiness scores of the subjects before and after receiving ACP education. A paired *t* test requires the assumption that the independent variable is a dichotomous nominal-level variable and the dependent variable approximates an interval-scale characteristic (Polit, 2010). The independent variable for this study was whether or not the subject received ACP education. The dependent variable was the subject's ACP readiness score on the ACP ES4.

Knowing a paired *t* test was the test that would be used as part of the statistical analysis of the data, it was also used to determine the sample size for this study. Polit and Beck (2012) stated a majority of nursing studies involve effect sizes between .20 and .40. To achieve a significance level of $\alpha = .05$ with an effect size of .40 ($d = .40$), and a power of .80, a sample size of 99 subjects ($N = 99$) was the target sample size for this interventional study.

Chapter 4: Results

Sample Characteristics

The convenience sample initially was comprised of 45 adults who were recruited over a 4-week timeframe from February 19 to March 11, 2020. The study sample primarily consisted of adults, a majority of which were Caucasian followed by smaller numbers of African American, Hispanic, and Asians, respectively. The duration of the study was curtailed by the outbreak of the coronavirus (COVID-19) and the suspension of student clinicals by Riverside Health System and Radford University. At the time the recruitment ended, of the 45 subjects enrolled, 10 were lost to follow-up and one subject passed away 2 days after the initial intervention, leaving a sample size of 34 subjects for analysis. A majority of the subjects, 47%, were over the age of 65 with the remaining subjects' ages ranging from 35 to 65, with one subject being less than 35 years of age (Table 1). Fifty-nine percent of the subjects were male and 41% were female. The sample population was fairly diverse as 70% of the subjects self-reported being White, 27% reported being Black, and 3% reported being other, primarily Indian in ethnicity. The marital status of the subjects varied: 44% were married, 24% were widowed, 17% were divorced, and 15% were single. A majority of the subjects obtained a high school degree, 68%, followed by 18% who obtained a bachelor's degrees, 5% obtained graduate degrees, and the remaining 9% reported not graduating from high school.

Table 1

Demographic Characteristics of the Sample

Demographic Characteristics	**Category**	**Value, No. (%) of total (n = 34)**
Age		
	Less than 35 y.o.	1 (3%)
	35 - 44 y.o.	2 (6%)
	45 - 54 y.o.	6 (18%)
	55 - 64 y.o.	9 (26%)
	Over 65 y.o.	16 (47%)
Gender		
	Female	14 (41%)
	Male	20 (59%)
Race/Ethnicity		
	Asian	0
	Black	9 (27%)
	Hispanic	0
	White	24 (70%)
	Other	1 (3%)
Educational attainment		
	Less than high school	3 (9%)
	High school diploma or GED	23 (68%)
	Bachelor’s degree	6 (18%)
	Graduate degree	2 (5%)
Marital status		
	Single	5 (15%)
	Married	15 (44%)
	Divorced	6 (17%)
	Widowed	8 (24%)

Note. Adapted from “Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors” by Sudore, R. L., Stewart, A. L., Knight, S. J., McMahan, R. D., Feuz, M. Miao, Y., . . . Barnes, D. E., 2013, *PLoS ONE, 8*(9), e72465.

The diabetic-population-specific sample characteristics describing the subjects’ type of diabetes, duration of disease, and self-reported health status were informative (Table 2). A majority of the subjects, 91%, were diagnosed with Type 2 DM, while three subjects, or 9%, were diagnosed with Type 1 DM. Surprisingly, most of the subjects, 38%, had been diagnosed with diabetes within the past 5 years, 24% had been diagnosed between 10 and 10 years ago, 14% between 10 and 15 years ago, and 24% have had diabetes over 15 years. Given a majority of the subjects, 47%, were over the age of 65, one would have thought a majority of the subjects would have been diagnosed with diabetes for a longer period of time. Next, with regard to self-reported health status, 9% reported poor health, 12% were uncertain of their current health status, 12% considered themselves in excellent health, while a majority of the sample, 67%, considered themselves to be in good health.

Finally, the ACP characteristics of the sample indicated only 23% had experienced a previous health care crisis in which they had lost consciousness and relied on another individual to make health care decisions on their behalf. This is in contrast to the higher percentage of subjects, 56%, who had prior experience acting as HCAs, making health care decisions for loved ones who were unable to during a health crisis.

Table 2

Diabetic-Specific and Prior Experience Characteristics of the Sample

Characteristics	**Category**	**Value, No. (%) of total (n = 34)**
Type of diabetes		
	Type I	3 (9%)
	Type II	31 (91%)
Years diagnosed with diabetes		
	Less than 5 years	13 (38%)
	5 to 10 years	8 (24%)
	10 to 15 years	5 (14%)
	Over 15 years	8 (24%)
Self-reported health status		
	Poor health	3 (9%)
	Good health	23 (67%)
	Excellent health	4 (12%)
	Uncertain	4 (12%)
Prior ACP experience		
	Prior personal health crisis experience	8 (23%)
	Prior experience acting as a health care agency	26 (77%)

Note. Adapted from "Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors" by Sudore, R. L., Stewart, A. L., Knight, S. J., McMahan, R. D., Feuz, M. Miao, Y., . . . Barnes, D. E., 2013, *PLoS ONE, 8*(9), e72465.

Major Project Variables

Sudore et al.'s (2017) Advance Care Planning Engagement Survey*,* 4-item version (ACP ES4), served as the pretest and posttest for this study. The 4-item version consisted of four questions specific to the process measure of readiness (Sudore et al., 2013). A subject's level of readiness was scored according to the subject's response for each question and the Likert scale point value assigned to that response (Sudore et al., 2013). Level of readiness scores were calculated for each of the four questions and then an overall level of readiness score was calculated by averaging the subject's responses to all four questions before and after the educational intervention (Sudore et al., 2013).

A review of subjects' responses to each of the four questions was conducted (Table 3). Overall, subjects' responses to all four questions reflected increased readiness to discuss AD with family and providers. The responses to the first question regarding readiness to discuss future plans of care with an HCA moved from 32% of the sample being fairly ready to 50% of the sample being extremely ready to speak with their HCA about future plans of care. For the second question, 35% of the sample were extremely ready to discuss an AD with their providers prior to the education. This increased to 50% after the educational intervention. This pattern of increased readiness to engage in ACP reported by the majority of the sample was also observed with the responses to the third and fourth questions regarding signing official papers.

Independent Variables. The independent variable for this study was the ACP education provided. The ACP education provided consisted of an overview of the unpredictable trajectory of diabetes, the limits of life-saving measures, and the benefits of ACP and the Five Wishes® advance directive document.

Table 3

Pretest and Posttest Readiness Responses

ACP Engagement Survey, 4-item version Readiness Questions	Pretest Readiness Responses n (%)	Posttest Readiness Responses n (%)
How ready are you to talk with your decision maker about the kind of medical care you would want if you were very sick or near the end of life?		
Not at all	2 (6%)	0
A little	4 (12%)	1 (3%)
Somewhat	8 (23%)	6 (18%)
Fairly	11 (32%)	10 (29%)
Extremely	9 (27%)	17 (50%)
How ready are you to talk with your doctor about the kind of medical care you would want if you were very sick or near the end of life?		
Not at all	1 (3%)	1 (3%)
A little	3 (9%)	0
Somewhat	8 (24%)	5 (15%)
Fairly	10 (29%)	11 (32%)
Extremely	12 (35%)	17 (50%)
How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?		
Not at all	0	0
A little	8 (24%)	4 (12%)
Somewhat	7 (20%)	6 (17%)
Fairly	8 (24%)	5 (15%)
Extremely	11 (32%)	19 (56%)
How ready are you to sign official papers naming a person or group of people to make medical decisions for you?		
Not at all	1 (3%)	0
A little	3 (9%)	1 (3%)
Somewhat	7 (21%)	4 (12%)
Fairly	10 (29%)	7 (21%)
Extremely	13 (38%)	22 (64%)

Note. Adapted from “Measuring advance care planning: Optimizing the advance care planning engagement survey” by Sudore, R. L., Heyland, D.K., Barnes, D. E., Howard, M., Fassbender, K., Robinson, C.A., . . . You, J.J., 2017, *Journal of Pain and Symptom Management, 53*(4), 669-6681.e8.

Dependent Variables. The primary dependent variable for the study, ACP readiness, was measured using the ACP ES4. Additional secondary outcome measures, obtained during a follow-up call conducted 2 weeks after the office intervention, were whether the subject (a) discussed ACP with a family member, (b) designated an HCA, and (c) completed an advance directive.

Sudore et al.'s (2017) ACP ES4 provided the subjects' level of readiness scores for each of the four questions and then an overall level of readiness score was calculated pre-intervention and post-intervention to determine if ACP readiness improved following an educational intervention of diabetes disease progression and the Five Wishes® advance directive form.

Research Question and Hypothesis Statement Analysis

The research question for this study, among diabetic patients presenting for a primary care office visit, how receiving ACP education would improve readiness to discuss AD compared to readiness prior to receiving ACP education, was answered by the following statistical analysis. Measures of central tendency including the range, mean, and standard deviation (*SD)* for both the pretests and posttests were examined. The mean pretest readiness scores ranged from 6 to 20 out of 20 possible Likert points (pts). The mean pretest ACP readiness scores were 15 pts, *SD* of +/- 4 pts. The mean posttest ACP readiness scores improved, as indicated by increased values across all measures. The mean posttest ACP readiness scores ranged from 12 to 20 pts. The mean posttest ACP readiness score increased to 17 pts, *SD* +/- 3 pts.

In order to answer the research question and test the hypothesis statements, a paired *t* test was conducted. The null hypothesis (H_0) postulated providing education on ACP to diabetic patients during primary care office visits does not improve their readiness to discuss advance directives. The alternative hypothesis (H_1) postulated providing education on ACP to diabetic patients during primary care office visits improves their readiness to discuss advance directives. Several assumptions were made when considering the *t* test for data analysis. The assumptions included the subjects who met the inclusion criteria were randomly sampled upon presenting to the family practice office (Polit, 2010). The next assumption was that the dependent variable, ACP readiness score, was presumed to be normally distributed within the two populations, before and after receiving ACP education (Polit, 2010). Finally, the homogeneity of variance was ignored as the sample sizes were equal (Polit, 2010).

No prediction was made regarding the possible direction of the H_1, and as a result, a two-tailed *t* test was chosen for the analysis (Polit, 2010). The *t* test measured the differences in the ACP readiness score means before and after receiving ACP education for the sample (Polit, 2010). Conducting a two-tailed *t* test ensured the critical regions under the curve were examined prior to rejecting the H_0, which would avoid committing a Type I error, incorrectly rejecting the H_0 (Polit, 2010).

The two-tailed paired *t* test results revealed the mean pretest ACP readiness score was statistically different from that of the mean posttest ACP readiness score ($p < .01$) (Table 4). The computed absolute value of $t = 2.912$ indicated the H_0 should be rejected (Polit, 2010). The effect size, Cohen's $d = .70$, is considered large and indicated the power of the paired *t* test was great, which confirmed the mean difference between the scores was strong and the degree to which the H_0 was wrong (Polit, 2010). In summary, the H_0 should be rejected. The paired *t* test indicated the H_1, providing ACP education to diabetic patients in primary care does improve readiness to discuss advance directives.

Table 4

Two-Tailed Paired *t* Test and Effect Size for Initial and Final ACP Readiness

Outcome	**Pretest Mean (SD)**	**Posttest Mean (SD)**	***t***	***df***	***p***	***d***
ACP Readiness	15.0 (4.0)	17.2 (2.8)	- 2.912	33	< .01	.70

Note. Adapted from "*t* Tests: Testing Two Mean Differences," *Statistics and Data Analysis for Nursing Research* (2nd ed.) by Denise F. Polit (2010). Upper Saddle River, NJ: Pearson.

The follow-up questionnaire assisted in identifying if any of the subjects experienced a change in ACP behavior by reporting they had discussed ACP with a family member, named an HCA, or completed an advance directive. The results indicate of the 34 subjects enrolled, 26, or 77% of the sample, reported discussing the Five Wishes® advance directive form with a family member after receiving the ACP education in the family practice office (Table 5). The same number of subjects, 26, or 77% of the sample, designated an HCA after receiving the ACP education in the office. The last question on the follow-up questionnaire indicated 11 subjects, or 32% of the sample, experienced a change in their ACP behavior stating they had completed the Five Wishes® advance directive form in response to the ACP education received during the study. An additional

19 subjects, 56% of the sample, intended to complete the Five Wishes® advance directive within the next 3 months.

Table 5

Follow-Up Questionnaire Frequency Distribution

Follow-Up Questionnaire	Category	**Value, No. (%) of total (n = 34)**
Discussed advance directives with a family member following the intervention		
	Yes	26 (76%)
	No	6 (18%)
	Plan to complete within 3 mos.	2 (6%)
Designated a health care agent following the intervention		
	Yes	26 (76%)
	No	6 (18%)
	Plan to complete within 3 mos.	2 (6%)
Completed an advance directive following the intervention		
	Yes	11 (32%)
	No	4 (12%)
	Plan to complete within 3 mos.	19 (56%)

Note. Adapted from "Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors" by Sudore, R. L., Stewart, A. L., Knight, S. J., McMahan, R. D., Feuz, M. Miao, Y., . . . Barnes, D. E., 2013, *PLoS ONE, 8*(9), e72465.

Summary of Data Results

The aim of this research study was to determine if providing a sample of diabetic patients in Newport News, VA with ACP education, using the easy-to-understand Five Wishes® document, would improve their readiness to initiate advance directivediscussions with their family and providers. Building upon the current trend in primary care of diabetic patients engaging in shared decision-making conversations and co-managing of their disease, this study intended to contribute new knowledge regarding the benefits of including advance care planning discussions as a routine part of their diabetic care. The study attempted to determine if informing diabetic patients about their possible future disease progression, including complications and premature death, limits of life-saving measures, and the benefits of a well written AD form, Five Wishes®, would increase their readiness to discuss ADs earlier in their disease process. The results of the data analysis, represented by the results of the paired *t* test, confirmed providing education on ACP to diabetic patients during primary care office visits improves subject readiness to discuss ADs with their family and providers. The majority of the sample, 77%, reported discussing ADs with their family after the intervention and close to a third, 32%, reported completing the Five Wishes® form within 2 weeks of the intervention. An additional 56% of the subjects reported they intended to complete the Five Wishes® AD form within 3 months.

Chapter 5: Discussion

Relationship of Findings to Prior Research

The concept of ACP education having the ability to improve readiness was reported by Zwakman et al. (2018) following a systematic review of 20 articles exploring the ACP experiences of patients with life-threatening and life-limiting diseases, including diabetes. This study supported Zwakman et al.'s (2018) finding that ACP education improves ACP readiness. Almost all of the cross-tabulations analyzed during this study involving the subjects' characteristics and ACP readiness, indicated the subjects, no matter what their background, reported increased ACP readiness after receiving ACP education in the family practice office. The mean pretest readiness scores ranged from 6 to 20 out of 20 possible Likert-points (pts). The mean pretest ACP readiness score was 15 pts with a standard deviation (*SD*) +/- 4 pts. The mean posttest ACP readiness scores improved as indicated by increased values across all measures. The mean posttest ACP readiness scores ranged from 12 to 20 pts. The mean posttest ACP readiness score increased to 17 pts, *SD* of +/- 3 pts. This study's results were in line with those of Kermel-Schiffman and Werner (2017), who conducted a systematic review of 37 studies and found a majority of the studies indicated education-based interventions improved ACP knowledge, which in turn improved ACP readiness.

An extensive literature search identified a limited number of studies specifically involving ACP and the diabetic population. Only two studies were identified, a qualitative study of 14 diabetic patients in Australia and a survey of 27 insulin-dependent diabetes patients in Canada. Savage et al. (2012) conducted the qualitative study of 14 diabetic patients and found only one had completed an advance directive, a 7% advance directive completion rate. Savage et al. (2012) stated one reason the diabetic patients reported they had not completed an advance directive was that the patients did not believe they needed to have an advance directive. These findings coincided with those of Hash et al. (2018), who conducted a survey of 305 older adult participants and found diabetics were less likely to complete advance directive due to a lower self-perceived disease burden. This perception of a lack of need for an advance directive among diabetic patients was also directly observed during this study. When initially providing the overview of the study for the diabetic patients presenting to the family practice office, many of the subjects were unaware of the unpredictable disease trajectory of diabetes, specifically the increased risk of heart attacks and strokes, which often result in loss of consciousness and possible need for a HCA to make decisions on their behalf. Initially, none of the diabetic patients enrolled in the study had an AD, but after participating in the study, 32% of the sample completed an AD within 2 weeks and an additional 56% of the subjects intended to complete their AD in the next 3 months.

Dunning et al. (2016) identified that a common challenge for patients and providers was determining when the best time was to discuss ACP. Initial recommendations were to use end-of-life (EOL) prognostic tools such as the Gold Framework or the Karnofsky Performance Scale (Dunning et al., 2016). Subsequently, Dunning and Martin (2016) developed a list of diabetes-specific triggers for initiating ACP discussions, which included when a patient has been diagnosed with diabetes for greater than 10 years. The cross-tabulation of subject age and its relationship with ACP readiness confirmed Dunning and Martin’s (2016) recommendation, as all the subjects’ mean readiness scores increased directly along with the increase in the number of years the subjects had been diagnosed with diabetes.

Nouri et al. (2019) conducted a cross-sectional study of 1,400 patients who received ACP education and concluded easy-to-understand education materials were the most important factor for improving ACP readiness. The use of the Five Wishes® AD form for this project was a strong contributing factor to the success of this study. The Five Wishes® form was written in plain language at an eighth-grade reading level and includes descriptive sections on personal, emotional, and spiritual preferences for consideration (Aging with Dignity, 2019). Wichersham et al. (2019) conducted a pair-matched cluster randomized study in six primary care practices including 2,748 patient encounters and found both patients and providers preferred the Five Wishes® form over the state of Oklahoma’s current AD form due to its ease of use. The success of the Five Wishes® form has been validated in this study as evidenced by the 32% AD completion rate with an anticipated additional 56% more AD completions in 3 months’ time. This study’s AD completion rate, 32%, exceeded that of Atherton (2019), 26.2%, who implemented the Five Wishes® advance directive form in a 16-week trial at a Northern Arizona family practice office.

Observations

When researching this topic and developing the research question for this study, the limited number of two studies that have been conducted on ACP within the diabetic patient population was surprising. The two studies conducted specific to this patient population were qualitative in design and were comprised of small sample sizes. Toth et al. (1998) studied 27 Canadian insulin-dependent diabetics, followed by Savage et al. (2012), who studied 14 Australian diabetics. These studies, specific to ACP within the diabetic patient population, reported diabetics want to be involved in shared decision-making discussions and recommended those discussions be held earlier in the diabetic disease process when patients were capable of making these decisions for themselves. Following an extensive literature review, no further studies involving diabetics and ACP were identified, including within the United States, which prompted this study being conducted.

During the study, it was interesting to observe subjects would initially state they only had a limited amount of time to participate in the study, but once the educational intervention began, many of the subjects took time to ask questions and share past experiences they had with health crises, whether personal or those of a loved one. A majority of the subjects were not aware diabetes is considered a life-threatening, life-limiting disease. Subjects shared they were aware of DM's microvascular complications involving their vision, kidneys, and sensation in lower extremities, but admitted they were not aware of the macrovascular complication of atherosclerosis placing them at increased risk for heart attacks and strokes. This may explain why many of the diabetic patients stated they had not considered completing an AD in relation to their having DM as they did not feel ill, a low self-perceived disease burden, the same finding as Hash et al. (2018), or were not aware of the life-threatening complications of DM.

There were two statistics included in the ACP educational intervention that seemed to impact the subjects the most. The first statistic was several studies indicated diabetic patients often experience a shortened life expectancy, a loss on average of 8 years of life, as compared to the general population (Dunning et al., 2018; Roper et al., 2001). The second statistic, which also seemed to impact the subjects the most, was a statistic provided by the International Diabetes Federation (2019) that reported a diabetic patient dies approximately every eight seconds.

When discussing the limits of life-saving measures, a majority of the diabetic subjects verbalized understanding that the likelihood of recovering fully following cardiac arrest and resuscitation was minimal. This topic elicited a good amount of discussion from the subjects as they reflected back on prior experiences with loved ones who had arrested, all of whom did not return to baseline. Several of the subjects shared they had experienced hypoglycemic episodes and had lost consciousness, including a young Type 1 diabetic. These subjects shared how uncomfortable it was to wake up in an ambulance and not know what had happened. The youngest subject in the study stated she intended to talk with her mother and complete the AD so that if she should experience another loss of consciousness, her mother would know her wishes for her care.

When initiating the discussion of the benefits of completing an AD, most of the older subjects admitted they had intended to complete an AD but had just not gotten around to it yet. Time constraints and difficulty scheduling time to get together with family to discuss ACP were the most often shared reasons for not completing an AD. One subject shared his first wife died unexpectedly years ago. The subject said it was a very difficult time in his life as her death was so unexpected and it hit him hard. It took him months to recover. The subject went on to say one day when he began to clean out his wife's closet, he came upon her purse and wallet. During this time, the subject became emotional and tearful. He stated when looking through her wallet, he came across his first wife's driver's license and was shocked to find out she was an organ donor and he never knew it. The man stated he was so upset to find this out months after her death because the couple had not discussed her wishes prior to her death, and he was unable to carry out her wishes. At this point the subject began to cry, saying he was upset because he was unable to do this one last act for her, to fulfill her wishes of becoming an organ donor. After the patient recovered emotionally, he stated he intended to take the Five Wishes® AD form home to discuss further with his second wife that evening. Unfortunately, 2 days later, I was informed this subject had passed away unexpectedly of what appeared to be a heart attack.

The Five Wishes® AD form was well received by the subjects in this study, which confirmed the findings of Atherton (2019) and Wichersham et al. (2019) that patients report the Five Wishes® form was easy to complete. Several of the subjects commented on how straightforward the form was and were surprised the document only required the signature of two witnesses and was legal in the state of Virginia. A few of the subjects mentioned the challenge with completing an AD was the time it takes and also having family present. The subjects were informed the form was easy to understand, did not require an extensive amount of time, and family members did not have to be present to complete the Five Wishes® form. The added benefit of the Five Wishes® form was that it is available online for family members to review the content from afar if needed. Multiple subjects requested an additional copy of the Five Wishes® form for their spouses to complete. The user-friendly format of the Five Wishes® AD form contributed greatly to the study's 32% AD completion rate.

The findings of this study indicated ACP education provided earlier in the diabetic disease process did improve diabetic patients' ACP readiness to discuss ADs with their family and providers. The findings of this study are reassuring as they coincided and supported the previous findings and recommendations of the two previous studies on the topic. These findings also aligned with the recommendations of the ACoP, IOM, and CDC to introduce ACP into primary care earlier in disease processes when patients are capable of making decisions regarding future care for themselves (ACoP, 2015; CDC, 2012; IOM, 2014).

Evaluation of the Theoretical Model

Goodwin et al.'s (2002) Advance Directive Decision-Making Model (ADDMM) provided a strong theoretical framework for this research study, specifically the intervention, the ACP discussion. The ADDMM advocated for a holistic approach to ACP discussions, understanding that the discussions involved an active interaction of perceptions between both the researcher and the subject (Goodwin et al., 2002). The interactions of this study were beneficial and supported the achievement of the mutual goal of the ACP discussion, which was diabetic patients felt capable of making informed decisions regarding their future goals of care (Goodwin et al., 2002). The results of this study supported the use of the ADDMM as the theoretical framework as 32% of the subjects enrolled not only engaged in the ACP discussion, but also took the next steps in the process by designating a HCA and completing the Five Wishes® AD document by the end of the study.

When reflecting back on the development of this study, the literature review, and current evidence available on this topic, it was difficult considering if an additional variable would better explain or answer the research question posed. The reason for the initial lack of recommendation was based on the fact that several questions on the demographic questionnaire were derived directly from recommendations of previous studies on the subject, including those conducted by Dunning and Martin (2018), Freid et al. (2009), and Shaw et al. (2017). Dunning and Martin (2018) recommended examining the correlation between the number of years a patient had been diagnosed with diabetes and ACP readiness, while Fried et al. (2009) and Shaw et al. (2017) recommended exploring the influence of prior experience with a personal health crisis or acting as a HCA on ACP readiness. After reflecting further on the study, additional variables to explore further in relation to ACP readiness to consider would be to include level of subjects' prior knowledge of ACP, subjects' comorbidities, or most recent hemoglobin A1C levels, which could offer greater insight into the most significant motivators for diabetic patients to engage in ACP.

Limitations

The limitations of this research study included its small sample size, a convenience sample, obtained at a single center, with an underrepresentation of minority populations, which may impact the generalizability of this study to the large population of diabetics living in the United States. The next limitation was the study's short duration, as making health care decisions can be challenging and more time may have been needed for subjects to determine their plans for care moving forward. An additional factor with respect to the short duration of the study was the outbreak of the Coronavirus (COVID-19) in mid-March, 2020. Both Riverside Health System and Radford University suspended clinical rotations in response to the ever-increasing spread of COVID-19 within the United States. Several subjects apologized during the post-intervention phase of the study, the follow-up phone call, for not completing their Five Wishes® AD form as intended due to the disruption COVID-19 had caused in each of their daily lives. A final limitation may be the lack of incorporating a control arm of additional advance care planning decision tools available such as Riverside Health Systems Medicare Wellness AD form or Virginia's *As You Wish* AD form for comparison.

Implications for Future Research

The next steps in order to develop further knowledge in this area of study would be to continue to build and expand on the findings of this study. Future research in this area should include studies with larger, randomized, heterogeneous samples of diabetic patients. Additional considerations would be to conduct future studies at multiple outpatient clinical settings over a longer period of time. A final recommendation for future research would be to further explore the use of the Advance Directive Engagement Survey to further validate its use in this field of research (Sudore et al., 2013).

One way to improve upon the design of this study would be to modify it by extending the duration of the study. An initial option would be to move to a multiple intervention design and spread out the delivery of content of the ACP discussion over two to three office visits to allow more time for the subjects to assimilate the information provided, apply the new knowledge to their personal circumstance, and reach a decision that is right for them as recommended by Cleary (2016) and Messinger-Rapport et al. (2009). A second option would be a basic pretest-posttest design with repeated follow-ups (Polit & Beck, 2012). A third option would be to move to a crossover design beginning with an initial ACP discussion with the subjects and then invite the subjects to return with a family member for the second visit for a follow-up shared decision-making discussion on ACP.

One aspect of the study that I would not recommend modifying would be the use of Goodwin et al.'s (2002) Advance Directive Decision-Making Model as the theoretical framework of the study. The model provided a solid foundation for conducting the study's intervention, the ACP educational session. The ACP educational sessions were successful as a result of following the model's premise that the interaction between the researcher and the subject is one of mutual goal attainment. The goal of the discussion was to improve diabetic patients' perceptions of their health status and empower them to engage in the act of decision-making and move forward in the ACP process by selecting one action over the alternative of doing nothing (Goodwin et al., 2002).

Implications for Practice

The significance of this study's results for clinical practice was that this study has provided an evidence-based best practice for offering diabetic patients ACP education in primary care. This study determined ACP education did increase subjects' readiness to discuss ADs with family and providers as well as assisted the subjects in progressing along the ACP process to complete an advance directive. This study validated diabetic patients did benefit from receiving ACP education in primary care when they were relatively healthy and capable of making these difficult decisions for themselves prior to experiencing a possible health crisis.

An additional finding of the study to note was that many diabetic patients within the study were unaware of the potentially life-threatening complications of diabetes, especially the increased risk for unpredictable heart attacks and strokes. Providing patients with information regarding these significant complications of diabetes and the limits of life-saving measures improved their knowledge of the possible disease course. Coupling this knowledge with an opportunity to co-manage their future goals of diabetic care in the form of an AD is one of the best practices primary care providers can do for their patients' well-being.

Current diabetic clinical practice guidelines, including those of the American Diabetes Association and Veteran's Administration, do not mention ACP as part of long-term management of this unpredictable disease. This is in contrast to the current recommendations of the ACoP, IOM, and CDC for ACP to be initiated by both providers and patients at any age or stage of life as a routine part of primary care (ACoP, 2015; CDC, 2012; IOM, 2014). Providers in primary care are in a key position to impact change in the area of ACP by informing diabetic patients of their potential disease progression and provide them with an opportunity to exercise their right to self-determination by educating them about the benefits of ACP.

Education on ACP should be incorporated into all health care professional education curriculums. The education should encourage health care providers, physicians, advance practice nurses, and physician assistants to follow the recommendations of the ACoP, IOM, and CDC and initiate these discussions at any age or stage of disease and not limit these discussions for patients over the age of 65 or approaching end-of-life (ACoP, 2015; CDC, 2012; IOM, 2014). Providers should be educated to begin this practice by initiating ACP for all new patients, during annual exams or changes in patient's health status, and following recent hospitalizations (Lawrence, 2016).

When considering this study's implication to health policy, one recommendation would be to revise the Patient Self Determination Act of 1990 to go beyond its initial requirements that hospitals educate patients on ACP and expand the responsibility to all providers within healthcare who provide direct care to patients. A second recommendation would be for primary care providers, including advance practice nurses, to petition private insurers to reimburse providers, as Medicare has, for conducting these valuable conversations in primary care. Medicare introduced ACP common procedural codes (CPT) in January 2016 (ACoP, 2015). Frellick (2019) reported fewer than 3% of physicians are using the CPT codes, 99497 and 99498, for ACP. If private insurers would reimburse ACP discussions, this may offer an additional incentive for providers to begin conducting these much-needed ACP discussions earlier in patients' disease processes when healthy and capable of making these decisions for themselves.

Conclusion

The aim of this research study was to explore whether providing a sample of diabetic patients in Newport News, VA with ACP education using the easy-to-understand Five Wishes® document would improve patients' readiness to initiate advance directive discussions with their family and providers. This study did contribute new knowledge to the body of research in this area specific to diabetic patients by validating that providing ACP education to diabetic patients earlier in their disease process, while in primary care, does improve their readiness to take the first step in the ACP process and initiate discussions about advance directives with their family and providers. Recommendations for future research would be to conduct similar studies at multiple outpatient clinical settings over a longer period of time. The studies should include larger, randomized, heterogeneous samples of not only diabetic patients, but healthy, young patients as well.

This study supports the recommendations of the ACoP, IOM, and CDC that ACP occur at any age or stage of disease as a best practice in primary care. There is no reason for primary care providers to delay introducing ACP in primary care. By introducing ACP earlier, providers will be able to provide the end-of-life care their patient wished for and avoid placing undue stress on unprepared family members to make health care decisions for a loved one. Primary care providers can and should take the lead within the health care community to protect the autonomy of all their patients by educating them and their families about the many benefits of ACP before anyone experiences an unexpected health care crisis.

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Appendix A Informed Consent Form

RADFORD UNIVERSITY

Informed Consent

Title of Research: An Educational Intervention to Increase Diabetic Patients' Readiness to Discuss Advance Care Planning in Primary Care

Researcher(s): Sarah Gilbert, PhD, RN, GCNS-BC, Katie Katz, DNP, RN, FNP-BC, Wendy Downey, DNP, MSEd, RN, CNE, and Sheila Fuller, BSN, RN.

We are asking you to volunteer to be in a research study designed to explore if receiving education on advance care planning will increase diabetic patients' readiness to discuss Advance Directives. When you arrived for your appointment today an introductory letter was provided for you to read over before we met. If you decide to participate in the study, you will be assigned a random number to protect your confidentiality. You will be asked to complete a short survey before having an eight to ten-minute discussion on advance care planning. An Advance Directive is a form that is used to inform medical providers and family members about your future wishes for healthcare should you experience a crisis or decline in your health be unable to make those decisions for yourself. The entire process should take only fifteen to twenty minutes to complete. The advance care planning discussion will be provided using Five Wishes®, a well-established Advance Directive document, to explore your values and beliefs regarding future health care decisions in the management of your diabetes. Following today's discussion, you will be called in two weeks' time to complete a second short survey over the phone and to see if you have any remaining questions about the form. The follow-up should only take ten minutes to complete. The study will end after the follow-up call is completed. Your responses to the survey questions will provide the data collected for this study. Approximately a hundred people from Bruton Avenue Family Practice will be asked to participate in the study.

This study has no more risk than what you may find in daily life. Some of the questions you will be asked as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions asked, take a break, or stop your participation in this study at any time.

If you choose to volunteer to participate in the study you will be compensated for your time with a pen and note pad with an advance care planning reminder to "Do it for yourself. Do it for your family."

The direct benefit you may receive from participating in this study is the peace of mind knowing you have informed your family and provider of your wishes for future healthcare should you experience a health crisis or a decline in your health and become unable to make those decisions for yourself.

It is your choice whether or not to participate in this study. What you choose will not affect any current or future relationship with Bruton Avenue Family Practice or Radford University.

If you decide to be in this study, what you tell us will be kept in confidence unless required to report it by law. The study will be conducted in a private room within the Bruton Avenue Family Practice office. You will be assigned a random number to protect your confidentiality. The deidentified paper pre- and post- surveys will be secured in a locked file box and shredded once entered into the researcher's password-protected data files on a password-protected personal laptop and jump drive. All of the password-protected data files related to the study will be retained for three years following the completion of the study. After three years the data files will be deleted.

The data collected in this research study will be kept confidential. Participation in research may involve some loss of privacy. We will do our best to make sure that the information about you is kept confidential, but we cannot guarantee total confidentiality. Your personal information may be viewed by individuals involved in the research and may be seen by people including those collaborating and regulating the study. We will share only the minimum necessary information in order to conduct the research. If we present or publish the results of this study, your name will not be linked in any way to what we present.

If you have questions now about this study, please ask them now before beginning to participate in the study. If you have any questions later, you may contact Sheila Fuller at sfuller14@radford.edu. If this study raised some issues that you would like to discuss with a professional, you may contact Dr. Sarah Gilbert at sgilbert2@radford.edu

This study was approved by the Radford University Committee for the Review of Human Subjects Research. If you have questions or concerns about your rights as a research subject or have complaints about this study, you should contact Dr. Ben Caldwell, Dean of the College of Graduate Studies and Research and Research Compliance, Radford University, bcaldwell13@radford.edu, 1-540-831-5724.

You will be given a copy of this information to keep for your records.

If all of your questions have been answered and you would like to take part in this study, then please sign below.

______________________	____________________	____________
Signature	Printed Name(s)	Date

I/We have explained the study to the person signing above, have allowed an opportunity for questions, and have answered all of his/her questions. I/We believe that the subject understands this information.

______________________	____________________	____________
Signature of Researcher(s)	Printed Name(s)	Date

Appendix B Advance Care Planning Engagement Survey, 4-item

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***Advance Care Planning Engagement Survey*, 4-item version**

Subject : #*(same randomly generated number)* Date:____________

Please answer the following questions.

1. How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?
    a. Not at all
    b. A little
    c. Somewhat
    d. Fairly
    e. Extremely
2. How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?
    a. Not at all
    b. A little
    c. Somewhat
    d. Fairly
    e. Extremely
3. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
    a. Not at all
    b. A little
    c. Somewhat
    d. Fairly
    e. Extremely
4. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
    a. Not at all
    b. A little
    c. Somewhat
    d. Fairly
    e. Extremely

Note: Adapted from "Measuring advance care planning: Optimizing the advance care planning engagement survey" by Sudore, R.L., Heyland, D.K., Barnes, D.E., Howard, M., Fassbender, K., Robinson, C.A., & . . . You, J.J., 2017, *Journal of Pain and Symptom Management*, *53*(4), 669-681.e8.

Appendix C Demographic Questionnaire

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Advance Care Planning Demographic Questionnaire

Subject : #*(randomly generated number)* Date:____________

Please answer the following questions.

1. What is your current age?
    a. Less than 35 years old
    b. 35-44 years old
    c. 45-54 years old
    d. 55-64 years old
    e. Over 65 years old
2. What is your gender?
    a. Female
    b. Male
3. What is your race/ethnicity?
    a. Asian
    b. Black
    c. Hispanic
    d. White
    e. Other
4. What is your marital status?
    a. Single
    b. Married
    c. Divorced
    d. Widowed
5. What is your highest level of education?
    a. No high school diploma
    b. Diploma or graduate equivalent degree (GED)
    c. Bachelor’s degree
    d. Graduate degree

6. What type of diabetes have you been diagnosed with?
   a. Type 1 Diabetes
   b. Type 2 Diabetes
7. How long have you been diagnosed with diabetes?
   a. Less than 5 years
   b. Over 5 years
   c. Over 10 years
   d. Over 15 years
8. How would you rate your current state of health?
   a. Poor
   b. Good
   c. Excellent
   d. Uncertain
9. Have you ever experienced a health care crisis where you were unconscious and unable to make decisions for yourself?
   a. Yes
   b. No
10. Do you have any prior experience with making health care decisions for a loved one who was unconscious and unable to make decisions for themselves?
    a. Yes
    b. No

Appendix D Follow-Up Phone Call Questionnaire

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Follow-Up Phone Call Questionnaire

Subject : #*(same randomly generated number)* Date:____________

1. Have you discussed Advance Directives with anyone yet?
    a. Yes
    b. No
    c. Plans to within the next three months
2. Have you designated a Health Care Agent?
    a. Yes
    b. No
    c. Plans to within the next three months
3. Have you completed an Advance Directive?
    a. Yes
    b. No
    c. Plan to within the next three months

Appendix E Advance Care Planning Introductory Letter

RIVERSIDE
Bruton Avenue Family Practice

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Dear Valued Patient:

As you know, we at Riverside Bruton Avenue Family Practice strive to provide comprehensive primary care for the entire family. The Riverside Health System's mission is "to care for others as we care for those we love." With that in mind, our goal has been to establish and maintain lifelong medical relationships with our patients. We encourage you, our patient, to take an active role in your health and that of your family. Our practice is to listen first and then work together to develop a healthcare plan that best meets your needs.

Given our approach, we are always interested in pursuing opportunities to improve our practice. We are currently exploring a new process to engage more of our patients in earlier advance care planning discussions. The purpose of advance care planning is to better understand your values and beliefs and how they may impact your future treatment goals. We want to ensure you are aware of advance care planning and that we are aware of your preferences so that we may follow them in the future if needed. We encourage you to review the enclosed materials and speak with your family regarding your wishes prior to your next appointment.

If you already have an Advance Directive please bring a copy with you to your appointment. A copy can be scanned into your medical record for future reference. We would like to discuss your advanced care needs with you. You are welcome to decline this discussion if you wish. Our intent is only to inform you of your options and for us to become more aware of your beliefs regarding future care. It is especially important to determine who you would like to have make medical decisions for you if you were unable to make them. This information will be very helpful should an unexpected medical issue arise. By having this information now, we can accurately care for you as you wish in the future.

Beginning earlier advance care planning discussions will not only provide peace of mind for you and your family but also bring the practice in closer alignment with the latest recommendations of the American College of Physicians, Centers for Disease Control and Prevention, and the Institute of Medicine.

Sincerely,
Bruton Avenue Family Practice