A DEVELOPMENT AND VALIDATION OF THE ADVANCE PLANNING PREPAREDNESS SACLE (APPS)

RENEE MCLEOD-SORDJAN, DNP

A Dissertation

Submitted in Partial

Fulfillment

of the

Requirements for

the Degree

of

Doctor of Philosophy in Nursing

Adelphi University

College of Nursing and Public

Health

May 17, 2023

Dissertation Committee:

Dr. Yiyuan Sun, Chair
Dr. Patricia Donohue-Porter
Dr. Virginia Brown

Author Note

Renee McLeod-Sordjan https://orcid.org/0000-0003-1952-2792

Acknowledgment

In each tear, there's a lesson, makes you wiser than before, makes you stronger than you know, and each tear brings you closer to your dreams, no mistake, no heartbreak can take away what you're meant to be- (Mary J. Blige, 2010)

I want to express my sincere appreciation of those that have traveled along my second doctoral journey and inspired me to pursue lifelong learning. Dr. Priscilla Worral foretold, during my clinical doctorate, that I was traveling along a research doctorate path placing my head on the guillotine of clinical problems without evidence-based solutions. I thank her for guiding me and inspiring my development of clinical questions that could only be answered by research.

I want to thank my educational mentors for their guidance and coaching. To Dr. Joanne Singleton for aiding me to pursuit a career and advanced degrees in nursing education. To Dr. Anne Pierce who inspired my own human becoming as I read the works of Rosemary Parse. Special thanks to Dr. Donahue- Porter for her mentorship and support. Deep appreciation to my Chair Dr. Yiyuan Sun who taught me consistency, perseverance, and purpose. Thank you, Dr. Sun for helping me learn factor analysis and for aiding me in fulfilling my dream to learn complex quantitative analysis. I would also like to thank my other committee members Dr. Virginia Brown and Dr. Shan Liu who provided valuable feedback and aided my philosophical understanding of psychological preparedness and structural inequities in health care. I am also deeply indebted to the late Merle Mishel and Anne Hamric. I thank them both for spending their time in discussing their work on uncertainty and moral distress. Because of their theories and conceptual frameworks, patients with chronic illness are supported by nurses advocating for their autonomy.

The PhD Road was challenging and interrupted by personal pursuits, travails in work/life balances and a global pandemic. I could not have accomplished the pursuits of this degree without the inspiration of my family and loved ones. To my brother, Israel Charles McLeod for being my first teacher and the first in the family to achieve a graduate degree. To my mother and sister, Josephine, and Maxine McLeod whose heavenly spirits lift me up when the road is difficult. To my children Katiera and Aidan whose love and encouragement are the purpose for my life and my reasons for breathing. To my sisters Mary, Irene and nieces Ebony, Ceaira, & Tanisha and great nephews Malik, Karriem, & Jaelen who are proud of me even when Thanksgiving dinner was takeout.

I am also deeply indebted to my patients, students, colleagues, classmates, and friends who continually offered support and gently nudged me to get that dissertation done. I am truly blessed to have my Northwell Health family who provided me with encouragement and reminded me with each milestone in the Division of Medical Ethics and Hofstra-Northwell School of Nursing & PA Studies to get back on task with the PhD. I want to personally thank Dr. Kathleen Gallo, Dr. Lauren Sparber, Jennifer, Katie, Mike, Christina, Stefanie, Barbara C., Anne Marie, and my weekend phone warrior Barbara D. To my classmates Maria, Mary-Ellen, Jackie, Marie M., Terry, Irene M., Irene F., Sam, and Lani, thank you for the comradery and teamwork. I dedicate this completion to our heavenly team member Marie A.

To all my future PhD alums, you will never lose; you either win or you learn. I loved this PhD journey of learning because the wins are too numerous to list. With each tear, the lessons made me wiser, stronger, resolute, and able to be a better mother, sister, auntie, partner, friend, teacher, clinician, ethicist, and nurse. ***Ph**inally **D**one; Renee McLeod-Sordjan, DNP, PhD*

Table of Contents

List of Figures

List of Tables

Abstract

Background: Delayed advance care planning and costs of aggressive life sustaining treatments at end of life significantly contribute to the economic burden of healthcare in the United States. Dying trajectories, in most chronic conditions, have terminal prognostic uncertainties that do not address advance care planning by clinicians in a timely manner. Clinician and nursing barriers include perceptions of inappropriate timing, lack of skills in end-of-life communication and viewing readiness as a behavior rather than a death attitude. The purpose of this study is to develop and validate the measurement of psychological preparedness for ACP to aid in the understanding of readiness for AD completion.
Methods: A community sample of 543 participants was recruited for exploratory and confirmatory analysis of the Advance Planning Preparedness Scale (APPS). Psychometric properties were analyzed with structural equation modeling in a general population with chronic illness. Criterion validity was assessed with questionnaires measuring social desirability, health anxiety, readiness, uncertainty, acceptance, and struggle with illness.
Results: Confirmatory factor analysis developed a 35 item pool resulting in a five factor explained 53% of the cumulative variance of APP. Cronbach $\alpha = 0.96$ for the total scale and for the five subscales psychological comfort ($\alpha = 0.87$), desire to know ($\alpha = 0.88$), thinking ($\alpha = 0.84$) , willingness ($\alpha = 0.82$) and existential reflection ($\alpha = 0.79$) with a possible common factor ($\alpha = 0.84$). Model fit of the modified second order APPS(35) was good $\chi^2(521) = 1140.18$, $p=0.000$, $\chi^2/df = 2.19$, RMSEA= .048 and CFI=.92. Multiple regression indicated significant predictors of being very likely to complete AD in 30 days included routine discussion (OR .08, $p<.001$), preparedness (OR 4.08, $p=.03$) and uncertainty (OR 4.37, $p=.02$). These predictors explained 33% of the variance. When social desirability was controlled for acceptance and EOL discussion predicted 40% of the variance of preparedness ($R^2=.40$, $F(3,140)=31.61$, $p<.001$).
Conclusions: Results support the use of APPS as a valid and reliable instrument to measure the influence of psychological attitudes on individuals with chronic illness preparedness to complete advance directives. In future research, APPS-35 can be utilized in diverse populations to understand preparedness as a psychological attitude that influences EoL communication and advance directive completion.

Keywords: preparedness, uncertainty, readiness, thanatology, advance directives, advance care planning

Development and Psychometrics of the Advance Planning Preparedness Scale (APPS)

Advance care planning (ACP) is a complex process utilized to express personal preferences, values, and priorities with the goal of preparing for care at the end of life (EoL) (Bischoff, Sudore, Miao, Boscardin & Smith; 2013; Lum, Sudore & Bekelman; 2015; Sudore et al., 2018). The ACP process allows patients with chronic life limiting conditions to make decisions regarding aggressive life sustaining treatment (LST) at EoL. The ACP framework attempts to address the broader perspective of EOL within a collaborative decision making approach among patients, family members and clinicians.

The IOM (2014) report entitled "*Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life"* challenged health professionals to develop standards for ACP and EoL communication that are measurable, actionable, and evidence based. The Patient Self Determination Act of 1990 first formalized and required healthcare facilities receiving Medicare and Medicaid funding to provide every patient with information regarding advance directives and medical care wishes (Garrido, Balnoni, Maciejewski, Bao and Prigerson, 2015). Legislatively, in the U.S. and abroad, ACP is mandated within chronic disease management for patients expected by clinicians to die within one year (Sabatino, 2014).

Despite these efforts, uptake of advance directives (ADs) for patients with chronic illness has not occurred. An American study revealed that only 36% of U.S. adults had completed a living will and 32% had completed a durable power of attorney for health care document (McAfee et al., 2017). Among severely or terminally ill patients, fewer than 50 percent had an AD in their medical record (Kass-Bartelmes & Hughes, 2004). Among veterans 85 years of age or older, receiving care from the Veteran Healthcare System, only

46% had designated health proxies (Wu, Lorenz & Choddosh, 2008). Schickedanz et al., (2009) in a descriptive survey design of 143 participants aged 50 or older (mean age=61), found 90% had not completed an AD. Knowledge deficit related to health information existed in 17% of those without advance directives. There is a significant difference in any AD completion by patient type with the highest rates being among patients in hospice or palliative care (59.6 percent; 95% CI: 41.8, 75.1) and nursing home patients (5.1 percent; 95% CI: 42.1, 58.2) (Yadav et al., 2017). In summary, failures in improving advanced directive rates highlight the importance of examining the ACP process from both the system and the patients' perspectives.

In recent years, worldwide initiatives have developed systemic approaches to support recommendation for ACP to occur earlier in the trajectory of illness. Current initiatives in the United States include the paradigm of Physician Orders of Life Sustaining Treatment (POLST), in England the National End of Life Care Programme, in South Korea, the LST Decision Act, in Taiwan the Patient Right to Autonomy Act and internationally the Liverpool Care Pathway (LCP) (Bomba, Kemp & Black, 2012; Dunn et al., 2007). Germany has also adopted the POLST paradigm to address a legal mandate to ensure that ACP occurs for patients at EOL (Klingler et al., 2016). Clinically based advance directive programs share key elements: a facilitated process of EOL communication, documentation, and the development of systems and processes that ensure planning occurs (Hickman et al., 2004; Hickman et al., 2008). Yet, the assessment of patient attitudes that suggest psychological preparedness for ACP as a precursor to AD completion is lacking in the above paradigms.

Communication and explanation from a health care provider was strongly correlated with advanced directive completion rates. Rao, Anderson, Lin & Laux (2014) in a national study of 7946 Americans, that lack of awareness of advance directives, cited a perception that family members were aware of their EoL desires as the most significant factors for not completing advance directives. Racial, educational, and social determinants of health disparities such as lack of access to primary care were also factors in decreased completion rates of advance directives (Rao et al, 2014). According to Fried, Bullock, Iannone & O'Leary (2009), completion of ADs incompletely conceptualizes both factors and outcomes of ACP.

Expected outcomes of ACP are to provide patients with a sense of control while dying, however barriers prevent implementation. The dying process poses difficulties for patients and their caregivers. Khairrudin and colleagues (2020) conducted a qualitative study with 16 nurses to explore the perceived benefits and challenges of advance planning. Researchers suggested the public has limited understanding and acceptance of ACP. Nurses perceived difficulty in communicating ACP and barriers to advocating for advance directives.

Despite legislation and worldwide initiatives, ACP experts have suggested that focusing singularly on AD completion rather than EoL communication incompletely addresses the problem. Bernacki & Block (2014) conducted a narrative review of English language articles published between January 2006 and December 2014 with the term "end-of-life communication", "goals of care" and "advance care planning" in the title or abstract. The review elucidated patient and system factors that impede the ACP process. Patient factors included psychological emotions of denial and anxiety that fostered avoidance of EoL communication. Avoidance was characterized as increasing the likelihood of patient failure to engage in realistic ACP. Physician factors included lack of EOL communication training, prognostic uncertainty, and fear of dealing with the psychological and psychosocial issues invoked by ACP. Nurses' perceptions of ACP vary due to the challenges of communicating death, cultural norms, time constraints and clinical guidelines that are overly physician centric (Arnett et al., 2017). Researcher recommendations suggest the ACP paradigm should address improved communication respectful of patients' psychological fears and preferences. Moreover, clinicians should incorporate an understanding of patient's fears and emotions into the ACP process.

Communication aspects that mediate ACP outcomes are insufficiently addressed, including patients' emotion, prognostic awareness, goals of care and existential issues. Researchers at Duke University School of Medicine identified the need for alternative approaches focusing on quality EOL communication rather than merely advanced directive completion. Tulsky and colleagues (2017) reported on the identification of a research agenda for ACP and EOL communication in patients with serious illness. The broad range of research topics covered communication skills, instruments, patient education and models of care. Specific to ACP, research priorities included: the outcomes of ACP most important to clinical care, timing of ACP and best approaches to garner the best likelihood of goal-concordant care. Specific to emotions, research priorities included: identifying what emotions affect ACP decision making, the effect of emotions on ACP and how EOL communication influences patient's emotions. Therefore, researching patient's emotions and the influence of communication is a key strategic priority to improve the ACP paradigm.

Fried and colleagues (2010) investigated the ACP process and found individuals are in different stages of preparedness for different ACP components. The stages of ACP process mirrored the Transtheoretical Model of behavioral change, which includes precontemplation, contemplation, preparation, action, and maintenance. The activities involved in ACP varied among participants. For example, some participants completed a living will, but they had not shared it with their loved ones or their physicians. The study found participants employed cognitive/emotional and behavioral strategies to engage in the ACP process. For example, they have thought about health provider's recommendations, the benefits of having an ACP in place and the surrogates for healthcare decisions. They also took actions to seek ACP related information, assess their loved ones' readiness to discuss EOL issues and tailor communication with their loved ones.

In summary, AD completion rates are not optimal as an outcome for ACP. Research related to ACP has focused on advanced directive completion rates and EOL communication. Research suggests the importance of assessing readiness for ACP as a priority to design tailored EOL communication that can occur earlier in the trajectory of illness.

Scope of the Problem

Cost of EOL Expenditures in Elderly Population

United States annual deaths surpassed 2.5 million deaths for the first time in history due to a "graying" of America a decade ago. In 2018, persons aged 65 and over accounted for 2.1 million deaths in the United States (Murphy et al., 2021). More than two thirds of all deaths are caused by one or more of these five chronic diseases: heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes. Chronic diseases are responsible for seven out of 10 deaths in the U.S., killing more than 1.7 million Americans each year. (Buttoroff, Ruder & Bauman, 2017). Americans with more than 5 chronic conditions are 12% of the population but account for 41% of total health care spending (Buttoroff et al., 2017). More than 90% of the $4.1 trillion spent on public and private healthcare in 2021 went toward chronic and mental health conditions (Center for Medicare & Medicaid Services, CMS, 2021).

Chronic disease is responsible for a significant cost in Medicare expenditures, healthcare utilization and mortality in the United States. Chronic disease accounts for approximately 75 percent of aggregate healthcare spending or annually $ 5300 per person (Raghupathi & Raghpathi, 2018). Approximately 70% of the 2.5 million annual deaths resulted from chronic conditions such as cardiovascular disease, cancer, and chronic lung diseases (Herbert et. al., 2006a). Among the Medicare population, 90% of deaths were associated with nine chronic conditions: including dementia, congestive heart failure, diabetes, and chronic lung disease. There were particularly sharp increases in health care utilization in the last two years of life and in the number of Medicare patients who saw ten or more physicians during their last six months of life (Goodman et al., 2011; Nardi et al.,2016). In 2019, Medicare expenditures were estimated at $630 billion representing 15 % of the federal budget (Cubanski, Nueman & Freed, 2019). In this decade, these expenditures are expected to rise to $1.3 trillion due to the growth of the Medicare population and use of new modern technologies (Cubanski et al., 2019).

The IOM (2014) report attributed soaring costs of EoL care to prolonged hospitalization and lack of ACP. End of life (EoL) care comprises at least 32% of Medicare expenditures with 10% occurring in the last month of life (Cubanski, Neuman, Griffin, & Damico, 2016; Donley & Danis, 2011; Riley & Lubitz, 2010; Teno et al., 2013). Moreover, most of these expenditures result from life sustaining treatments (i.e., cardiopulmonary resuscitation and mechanical ventilation) with acute care hospitalization in the final month of life accounting for 78% of costs incurred in the last year of life (Zhang et al., 2009). In summary, improving the ACP process could address the cost expenditures related to unwanted interventions inconsistent with patient preference at EoL.

Increased ICU Utilization at EOL

Utilization of the intensive care unit (ICU) at EoL accounts for a significant financial burden, despite advances in palliative and hospice care. Approximately sixty percent of Medicare spending in the last six months of life occurs during the last thirty days (Krumholz, et al., 2015). Moreover, *the 2008 Dartmouth Atlas of Health Care*, reported that in the last six months of life, chronically ill Medicare beneficiaries spent more than 3 times as many days in the hospital and more than 10 times as many days in an ICU (Wennberg, Fisher, Goodman & Skinner, 2008). Goodman, Esty, Fisher & Chang (2012) reported fewer days at EOL spent in the hospital and increased hospice utilization by Medicare beneficiaries between 2003 and 2007. However, over the same period, the intensity of care increased, including a rise in the number of ICU days in the last six months of life.

The early decades of the new millennium did not demonstrate a reduction of ICU utilization in hospice patients. Although hospice use across the decade increased, in 2009, nearly one-third of patients at EOL utilized less than three days of hospice care. Of these late hospice admissions, 4.3% were preceded by hospitalization with an ICU admission and 14.2% of patient's experienced transitions of health care in the last three days of life (Teno et al., 2013). Weissman et al. (2020) analyzed 16,646,977 claims from 2006 to 2015 from all Medicare Fee-for-Service (FFS) beneficiaries for potentially preventable ICU hospitalizations. Among hospitalizations with ICU care, more than 2,580,378 (15.5%) were associated with a potentially preventable diagnosis and 6.3% of all ICU admissions were among patients at end of life. Therefore, strategies that address palliative care and ACP could reduce EOL ICU admissions.

Advance directive completion as a strategy to reduce the high utilization of Medicare spending at EOL, has demonstrated variable results. Nicholas, Langa, Iwashyna, & Weir

(2011) utilized the Medicare claims data for Health and Retirement Survey (HRS) respondents who died between 1998 and 2007 at age 65 years or older or after qualifying for Medicare through disability or end-stage renal disease to analyze advanced directive completion effects. The cohort included 3302 decedents with a mean age at death of 82.8 years. Fifty-six percent were women; 70% were hospitalized at least once in the last 6 months of life; 41% died in a hospital; 61% had either a living will or written durable power of attorney; and 39% completed a written, treatment-limiting advance directive. Advance directives were associated with lower spending in hospital referral regions with high average levels of EOL expenditures (−$5585 per decedent; 95% CI, −$10 903 to −$267), but there was no difference in spending in hospital referral regions with low or medium levels of EOL expenditures. Directives were associated with lower adjusted probabilities of in-hospital death in high- and medium-spending regions (−9.8%; 95% CI, −16% to −3% in high-spending regions; −5.3%; 95% CI, −10% to −.4% in medium-spending regions). Advance directives were associated with higher adjusted probabilities of hospice use in high- and medium-spending regions (17%; 95% CI, 11% to 23% in high-spending regions, 11%; 95% CI, 6% to 16% in medium-spending regions), but not in low-spending region.

Earlier ACP and AD completion could potentially lead to less EOL spending. Nicholas et al., (2011) performed logistic regression to understand the regional effect of advanced directive completion and Medicare spending. After adjusting for patient characteristics and hospital referral region-spending intensity, there was no difference in Medicare spending in the last 6 months of life for those with ($28 348; 95% CI, $26 698 to $29 999) and without advance directives ($29 352 [95% CI, $27 885 to $30 819]; difference, −$1004 [95% CI, −$3366 to $1359]) (Nicholas et. al, 2011). However, ADs specifying limits in treatment were more common in areas with lower levels of end-of-life spending. Differences in Medicare spending observed in higher utilization regions among those with advance directives were driven by lower inpatient spending ($7509, 95% CI, $3404-$11614).

Advanced care planning still occurs late in the trajectory of illness, despite CMS providing an opportunity for clinicians to bill Medicare for ACP in patients with serious chronic illness since 2016. Palmer, Jacobson & Enguidanos (2021) examined 133,234,642 fee-for-service Medicare claims. Researchers found a substantial increase in outpatient advance care planning claims between 2016 and 2019, however prevalence remained below 7.5 percent for all patient subgroups analyzed. Compared with patients without ACP, patients with serious chronic illness and late ACP still experience more intensive EOL care, including in-hospital death (aOR, 1.22; 95% CI, 1.19-1.26), hospital admission (aOR, 5.28; 95% CI, 5.07-5.50), intensive care unit admission (aOR, 1.57; 95% CI, 1.53-1.62), and emergency department visit (aOR, 3.87; 95% CI, 3.72-4.02) (Weissberg et al., 2021).

Advance directives have become increasingly popular but alone are insufficient to stem increasing rates of hospitalization and in hospital death. Silveira, Wiitala and Piette (2014) reviewed the Health and Retirement Survey (HRS) and performed a retrospective analysis of 6,122 respondents between 2000 and 2010 and were aged 60 and older at death. Advanced directive completion was positively correlated with hospitalization but negatively correlated with in-hospital death. Participants with completed ADs had higher adjusted odds of hospitalization (adjusted OR (aOR) = 1.45, 95% CI = 1.29–1.62, $p < .001$) but lower adjusted odds of hospital death (aOR = .80, 95% CI = .72–.89, $p < .001$). During the decade, AD completion increased from 47% in 2000 to 72% in 2010. However, hospitalization in the last 2 years of life increased from 52% to 71%, and in hospital death rates only decreased from 45% to 35%. After adjusting for confounding by sociodemographic characteristics, the trend in declining hospital death was negligibly associated with the greater use of advance directives. In summary, AD completion is incomplete in stemming a reduction of healthcare costs.

Structured ACP programs, which focus on patient preferences and EOL communication have demonstrated the ability to reduce healthcare costs. Klingler et al. (2016) conducted a systematic review evaluating the cost implications of ACP when EOL communication is included in the ACP paradigm. Only 7 studies of the 852 studies screened met inclusion criteria. Four of the studies were randomized controlled trials, one was a quasi-experimental study and two were observational studies. Klingler et al. (2016) demonstrated a reduction of healthcare costs by $1041 US dollars to $ 64,827 US dollars per patient in six studies, depending on the intervention period and type of patient. The above research suggests an urgent need for structured ACP programs that address the needs of patients with serious illness urgently. All studies found reduced costs through the professionally facilitated EOL communications with logistic regression demonstrating a relationship between costs and EOL communication.

End of life communication is associated with lower rates of life sustaining treatments and higher rates of palliative care. Wright et al. (2008) demonstrated in a longitudinal cohort design that EOL communication was associated with lower rates of ventilation (1.6% vs 11.0%; aOR, .26; 95% CI, .08-.83), resuscitation (.8% vs 6.7%; aOR, .16; 95% CI, .03-.80), ICU admission (4.1% vs 12.4%; aOR, .35; 95% CI, .14-.90), and earlier hospice enrollment (65.6% vs 44.5%; aOR, 1.65; 95% CI, 1.04-2.63). Furthermore, patients who engaged in communication related to ACP where significantly ($P < .001$) more likely to accept that their illness was terminal (52.9% vs 28.7%), prefer palliative medical treatment (85.4% vs 7.0%), and have completed a do-not-resuscitate order (63.0% vs 28.5%). Yet a key barrier to EOL communication by nurses and other clinicians is the perception that patients will have psychological distress.

In summary, EOL communication aids patients but the assessment of their psychological preparedness prior to the communication is unknown.

Nursing Response to Improving Preparedness

Improving the unique psychological needs of the dying through EOL communication has been a nursing priority for more than two decades. At the beginning of the millennium, the City of Hope Medical Center, and the American Association of College of Nurses (AACN) developed the EOL Nursing Education Consortium (ELNEC) curriculum to educate nurses and clinicians. Nurses have the unique opportunity to be present for patients and their caregivers, explain EOL options and advocate for them. Nurses are present as patients ponder their values and travel along their personal EOL journey. In being present, the nurse is immersed in the dying patient's situation, aware of, and committed to, the responsibility of both the nursing care and the patient (Parse, 1997; Vaillott, 1966). However, more than 80% of ICU nurses reported being unprepared educationally to provide EOL quality care to patients and their loved ones (Todaro-Franceschi, 2013). Nurses' perceptions of preparedness to care for dying patients was moderately associated with compassion ($r = .40$, $p < .001$) and weakly associated with compassion fatigue ($r = -.12$, $p < .01$) and burnout ($r = -.10$, $p < .05$). An assessment of patient's thoughts about ACP could aid nurses in providing quality EOL care.

Nursing science has advocated for the expansion of federally funded research initiatives to design, develop and test best practices in palliative care to improve access of ACP. In the first decade of the millennium an estimated 433 million federal dollars supported EOL research, however private dollars significantly decreased (National Institute of Nursing Research, 2013). Targeted efforts have been supported by initiatives by the National Institute of Nursing Research (NINR) including the establishment of the Office of End-of-Life and Palliative Care Research (OEPCR). In August 2011, NINR conducted a summit entitled the *Science of Compassion: Future Directions in End-of-Life and Palliative Care to identify* ways to advance research in EOL and palliative care. A key priority identified was researching differential interventions in marginalized populations to improve communication regarding advance care plans (Csakai, 2011). However, the most compelling nurse advocate for providing high-quality ACP and EOL communication was Amy Berman.

Berman (2015) provided a first-hand reflection in an op-ed in the Washington Post to CMS about her encounters with health care and her stage IV inflammatory breast cancer diagnosis. Berman described the importance and infrequency of goals of care EOL discussions. Her advocacy has translated to appointments on the National Quality Foundation, Geriatrics and Palliative Care Measures Committee, CMS' Partnership for Patient and Family Engagement Network and the Aging Task Force for Healthy People 2020. Berman's work encouraged CMS to encourage palliative goals of care and EOL conversations. Yet, a comprehensive approach to assessing patient preparedness for the goals of conversation has yet to be funded by nursing research.

Importance of ACP During COVID- 19 Pandemic

Psychological preparedness for ACP has had greater relevance during the pandemic caused by the novel severe acute respiratory syndrome-Coronavirus 2 (SARS-CoV-2) pandemic. The pandemic impacted older adults disproportionately from increased severity of illness, hospitalization rates and mortality (Farrell et. al., 2020). Yanez et al. (2020) reported that older adults aged 65 and greater had a 62 times higher rate of mortality when compared to younger ages (IRR = 62.1, 95% CI=59.7, 64.7). Lack of prior advance planning completion led to emergent crisis of EOL discussions. Completion of advance directives became necessary to ascertain patients who desired as well as would benefit from the limited healthcare resources of intensive care, mechanical ventilation, and cardiopulmonary resuscitation. Farrell and colleagues (2020) supported prior research that completion of ADs though necessary is insufficient to understanding the cultural and personal factors that impede EOL communication. In summary, an assessment of preparedness for ACP could aid in understanding the factors that would facilitate EOL communication.

Background of the Problem for Study

This section will present a critical discussion of literature related to psychological preparedness for ACP in patients with chronic disease.

Advanced care planning has been conceptualized as a process of health behavior change by which patients develop readiness for discussions about EOL (Fried, Bullock, Iannone, & O'Leary, 2009). This process includes clarifying patient's understanding of their illness, prognosis, and treatment options in the context of their values, beliefs, and goals for care over the entire trajectory of health and illness (Detering et al., 2010; Sudore et al., 2013; Farrell et al., 2020). The ACP paradigm seeks to honor the patient's preferences for goals of care and treatment if they should become incapacitated by life threatening illness.

A key limitation of the ACP paradigm is the lack of consensus of what constitutes the outcomes of a structured ACP intervention. Utilizing the Delphi method, Sudore et al. (2018) garnered consensus regarding the most important patient centered outcome domains and constructs that define successful ACP.

The ACP organizing framework was created by a panel of fifty-two expert researchers and clinicians from four countries. Moving beyond just advanced directive completion, the panel identified four specific outcomes of ACP: (1) ACP action outcomes (e.g., communication and documentation), (2) quality of care outcomes (e.g., concordant care and satisfaction), (3) healthcare outcomes (e.g., health status, mental health, and utilization) and (4) process outcomes (e.g., behavior and perceptions). The ACP outcome domains were created however validated measures have yet to be standardized.

Psychological preparedness, readiness and prognostic awareness were conceptualized and ranked by experts to be key constructs to be researched and considered in the ACP paradigm. For example, process outcomes describe the psychological process and dynamic properties of the individual that occurs to create the how and why one adopts a plan (Sudore et al. 2018). Behavioral change (e.g., readiness, knowledge, self-efficacy) and perceptions (e.g., barriers, facilitators, attitudes, and prognostic awareness) was characterized as process outcomes of the ACP process. Action outcomes specific to ACP measures an individual’s completion of the ACP process and includes EOL communication of values/preferences and advance directive documentation. Process outcomes precede the action of completing documentation as well as the EOL communication of one’s values and preferences. Moreover, readiness to engage in ACP was ranked as the highest domain internationally when addressing process outcome measures within the ACP framework. In summary, identifying readiness and psychological perceptions was ranked as a priority and first step in the ACP paradigm by international experts. It is important to assess patient psychological preparedness to structure EOL communication efforts.

To date existing tools inadequately capture psychological preparedness. For example, there are two existing instruments that aim to capture readiness for EoL care; the Advance Care Planning Readiness Instrument (ACPRI; Calvin, 2006) and the Readiness for End-of-Life Conversations Scale (REOLC, Berlin et al., 2021). Calvin (2006) reported weak internal consistency of the ACPRI scale (Cronbach's alpha .73). Similarly, Berlin et al. (2021) performed an exploratory factor analysis to assess readiness for EOL conversations and validated REOLC's readiness scale (Cronbach's alpha .84). Recently in Japan, Sakai, and colleagues (2022) developed the Readiness for Advance Care Planning Scale (RACP) based upon the TTM framework. Both the REOLC scale validated in German and the Japanese RACP would require cross cultural validity study. The decision-making culture and medical legal systems abroad differ significantly from American culture. Therefore, no existing instruments capture the patient's perspective or psychological preparedness for ACP.

Clinician EOL Skills Do Not Equate to Preparedness

Previous literature studied clinicians' role and contributions in ACP communication. This poses a significant gap in the literature, as clinician skill does not equate to the patient attitude toward readiness for ACP. A metanalysis of EOL communication interventions performed by Walczak et al. (2016) retrieved sample of 109 articles that researched EOL communication interventions for health professionals, patients, caregivers, or other groups. Within the subset of articles six studies focused on patient focused interventions for ACP (Cornbleet et al., 2002; Chan & Pang, 2010; Grimaldo et al., 2001; Heyman & Gutheil, 2010; Jones et al., 2011; Uitdehaag et al., 2012). Research interventions included increasing knowledge regarding EOL communication and methods of communicating but omitted active ACP (Grimaldo et al., 2001; Heyman & Gutheil, 2010).

Clinician skills may influence a patient's psyche to accept and become prepared for ACP. However, clinicians often report lack of guidance to assess patients and family's preparedness for ACP conversations and do not know how to improve patients and family's preparedness. For example, Hutchinson et al. (2017) studied readiness for ACP using a qualitative study of nine patients, nine clinicians and seven family members. The study found clinicians used different methods to evaluate patient and family's preparedness. For example, some mention the topic and based on patient's response guide future conversation, while others wait for the patients to start the discussion. Some clinicians repeatedly mention the topic, driven by the hospital policy for paperwork completion, in the hope that patients would be ready at some point. These findings demonstrated the importance of a standardized tool for clinicians to evaluate preparedness to improve EOL discussion and ACP outcome. In addition, a comprehensive tool could help clinicians identify reasons for unpreparedness and thus restructure their communication strategies to improve patient's preparedness for ACP.

Psychological Distress: Not a Barrier for EOL Communication

End of life communication is associated with increased rates of completion of advance care plans. Wright et al. (2008) demonstrated in a longitudinal cohort design that EOL communication was associated with lower rates of ventilation (1.6% vs 11.0%; aOR, = 0.26; 95% CI, 0.08-0.83), resuscitation (.8% vs 6.7%; aOR=0.16; 95% CI, 0.03-0.80), ICU admission (4.1% vs 12.4%; aOR=0.35; 95% CI, 0.14-0.90), and earlier hospice enrollment (65.6% vs 44.5%; aOR=1.65; 95% CI, 1.04-2.63). Furthermore, patients who engaged in communication related to advance care planning where significantly ($p < .001$) more likely to accept that their illness was terminal (52.9% vs 28.7%), prefer palliative medical treatment (85.4% vs 7.0%), and have completed a do-not-resuscitate order (63.0% vs 28.5%). Yet clinicians reported a key barrier to EOL communication was the perception that that patient will have psychological distress.

Research findings are mixed regarding EOL discussions and psychological distress. Wright et al. (2008) in a longitudinal cohort of 332 dyads of patients and their caregivers, reported 37% (n=123) of patients reported EOL discussions before baseline. End of life communications were not associated with higher rates of major depressive disorder (8.3% vs 5.8%; aOR=1.33; 95% CI 0.54-3.32). Emanuel et al. (2004) developed a 133-question survey for terminally ill patients as part of prospective cohort study conducted in the United States. The initial EOL communication and survey results found little or no stress in 88.7% of participants in the initial test (n= 878) and 86.5% of participants upon retest (n=569). Moreover, 46.5% of terminally ill participants in the study found EOL discussions helpful. Jones et al. (2011) further evaluated satisfaction with ACP communication and concluded that ACP discussion does not increase anxiety for patients with advanced illness. These studies indicate that EOL communication should be tailored to individual patient's preparedness for ACP. Thus, ongoing assessment of patient's preparedness is necessary to initiate and improve EOL discussion.

In summary, EOL communication may not cause increased of psychological distress for patients. EOL communication is important, but the missing link is assessing readiness for patients to have EOL discussions.

Intrapersonal Factors Associated with Completion of Advance Care Planning

Research has attempted to ascertain the intrapersonal factors that do influence AD completion. Intrapersonal factors are defined as “characteristics of the individual, which influences behavior, such as knowledge, attitudes, skills, self-efficacy and developmental history” (Tripken, Elrod & Bills, 2018). Life events were characterized as triggers for psychological desire to become prepared. For example, verbatims of the focused group interviews cited the birth of a child and death of a loved one as invoking thought to engage in ACP (Banner et. al, 2019).

Prior experience with EOL issues is hypothesized to increase readiness for ACP. Ruff et al. (2011) hypothesized that prior knowledge and experience with EOL would increase AD completion. A cross sectional survey design was utilized with 325 participants to ascertain preferences related to planning for EOL, health care preferences at EOL, knowledge/opinions about hospice, and comfort communicating about EOL. Ruff et al. (2011) constructed a regression model for EOL communication. Results show that having a living will, prior knowledge of hospice, and higher educational level accounted for 18% of the variance in comfort with EOL communication ($R^2=.18$, $p < .001$). The researchers’ selection of participants who had prior history of experiences with EOL limits the generalizability of these findings to the general population. This research identified that factors affecting patient psychological preparedness to engage in EOL communication and complete an advanced directive is limited.

Experiences with EOL care has been associated with increased readiness of older adults to participate in ACP. Amjad et al. (2014) conceptualized readiness for ACP utilizing the TTM stages of change. In an observational cohort study, 304 participants were surveyed to assess experiences with personal illness and end-of-life care. Participants, aged 60 or older, were asked to respond yes or no to whether they had: a) faced a life-threatening illness; b) had a risky or major surgery; c) made a medical decision for someone who was dying; d) known someone who they believe had a bad death due to receiving too much medical care; e) known someone who they believe had a bad death due to receiving too little medical care; or f) experienced the death of a loved one who made his or her wishes about end-of-life known (Amjad et al., 2014).

Amjad et al. (2014) results demonstrated that prior EOL experience is associated with increased ACP behaviors. Having a life-threatening illness was associated with increased readiness to communicate with loved ones regarding life-sustaining treatment ($p = .03$). Prior experience with a “bad death” due to receiving aggressive medical care was associated with increased readiness to discuss quality of life but not readiness to discuss quantity of life. Prior history of making EOL decisions for others was associated with completion of a living will, EOL discussions with loved ones and EOL discussions with physicians. However, the researchers did not find an association between the individual’s health status, chronic comorbidities, and advanced directive completion. Major limitations of the study where researchers did not adjust their analysis for confounding variables and viewed readiness for ACP as a linear binary construct.

Meta-analysis of educational interventions demonstrated that intensity of the ACP discussions supports advanced directive completion in both acute and chronic populations. Alano et al. (2010) explored factors that might encourage patients to proceed with addressing EOL issues and complete advance directives. Five factors were associated with completion of advance directives including female gender (68% vs. 41%), Caucasian race (78% vs. 45%), higher education greater than high school education (93% vs. 78%), age greater than 85 years (26% vs. 16%) and religion; Catholic (45% vs. 37%) or Jewish (31% vs. 19%). In a multivariate regression analysis, Kim, and colleague (2021) found advance directives was associated with age over 75 years, higher education, income, presence of more than 3 chronic diseases, not desiring LST and death education. Leong and colleagues (2021) also supported age, marital status, education and prior EoL experiences as predictors of advance directives.

In summary, having been prepared by prior life experiences leads to increased ACP behaviors. Therefore, patients' perceptions and prior experiences are important attributes to consider in an assessment of preparedness for ACP and missing from current assessments of readiness for ACP. Intrapersonal factors related to advance directives completion in the literature are supported by an agreement with terminal disclosure, a positive relationship with clinical providers, understanding of life sustaining treatment and female gender. Although these factors may support the completion of the document, psychological readiness for ACP was not addressed.

Perceived Readiness to Participate in Advance Care Planning

Qualitative study has sought to assess readiness for advance care planning. Banner et al. (2019) highlighted those participants stated that preparedness involved a spiritual process. Although troublesome thoughts triggered a desire to prepare for ACP, participants did not engage in the ACP process. Hutchinson et al. (2017) qualitatively interviewed twenty-five participants (nine patients, nine clinicians and seven family members). Results illustrated that the ACP process requires reframing as patients and clinicians perceived ACP to be relevant when patients are close to EOL. A global theme was readiness for ACP was value laden. Perceived readiness for ACP by patients was viewed as only needing initiation as illness manifested itself. While clinicians associated ACP with death and dying, rather than preparing for and achieving quality of living at EOL. Thus, the clinician perspective of readiness for

ACP differs from the patient's perspective of perceived readiness.

Perceived readiness as an emotional and cognitive thought is a current gap insufficiently addressed in research. Tulsky et al. (2017) specifically cited emotion, prognostic awareness, spirituality, and existential issues were inadequately addressed by research in this area. McLeod-Sordjan (2013) also identified the lack of a valid assessment of the dying patient's mental preparedness as a major gap in current research that prevents an evaluation of the optimal timing to initiate ACP communication. In this study, readiness for ACP is synonymous with preparedness for ACP.

Gap in Research Related to Preparedness for ACP

This section will summarize the literature and present the research gap that supports the need to create a study to assess preparedness for ACP. Meehan and colleagues (2020) conducted a recent scoping reviewing ACP of 28 articles sampling adults with COPD. The occurrence of repeated acute care episodes was identified as appropriate timing to initiate ACP to help clinicians overcome perceiving prognostic uncertainty as a barrier to assessing readiness for ACP. Eighteen studies involved patients with approximately 40% (n=9) being qualitative. Most studies again reviewed the impact of clinician led interventions on ACP preparedness. One included a descriptive qualitative study of 12 individuals with moderate COPD indicated that assessment of preparedness for ACP should be performed throughout illness progression to reduce uncertainty (Nguyen et al., 2013).

Nguyen et al. (2013) proposed utilizing the TTM theory to determine readiness for ACP. In the single reported RCT of 95 individuals with COPD in Australia, prognostic awareness, and readiness prior to EOL communication was improved by nurse led facilitated EOL communication (Sinclair et. al, 2017). The paucity of studies that review EOL communication from the patient psychological perspective highlights a major gap in the scoping review. The studies included focused on clinician perceived barrier. Identifying transition points from the clinician perspective is an algorithm to address clinician distress related to prognostic uncertainty. There is a need to assess which patients have readiness for ACP while coping with prognostic uncertainty.

Bischoff et al. (2013) explored the ACP process to determine its impact on completion of ADs. A community based large cohort study obtained from the Health and Retirement Study (HRS) of 22,000 Americans over age 50 has been surveyed biennially sampled since 1992. The survey oversamples African Americans, Hispanic Americans, and Floridian residents. Bischoff et al. (2013) included 6942 deceased Medicare respondents between the years 1993 and 2007. Among the sample, 76% had engaged in the ACP process and with 26% completing all components; EOL discussions along with an advanced directive and a durable power of attorney.

The ACP process increased in the years after the SUPPORT trial (Pritchard et al, 1997), performed in 1997, to more than 50%. Older decedents, women, Caucasians, single individuals, higher income, and long-term residents of nursing homes were more likely to engage in ACP. Bivariable analysis and regression model was utilized to predict the prevalence of ACP and quality if end of life care. Preparedness for ACP and EOL communication were associated with quality of EOL care. Participants prepared for ACP were less likely to die in the hospital (39.2% vs. 49%; $p<.001$), less likely to spend more than two weeks in the hospital during the last month of life (1.3% vs. 14.1%, $p< .001$), and less likely to be admitted to the ER or ICU. The study concluded that conducting EOL communication, completing advance directives and having a durable power of attorney were key elements of the ACP process.

Clinician comfort with performing EOL communication has been the subject of most research related to ACP. Clinician fears and skills related to initiating EOL communication has been demonstrated as a barrier in ACP (Berlin et al., 2021). Clinician driven initiation of ACP is also a significant false assumption in research related to ACP. Health professionals are expected to interpret patient's readiness for EOL conversations through subjective cues. The impact of the COVID-19 pandemic illustrated that most adults with chronic illness have not been approached to have EOL conversations by their health care professionals despite being ready to have them. Moreover, usual EOL conversations that require significant time occurred hastily and in younger individuals (Bender et al., 2021). Initiation of an EOL conversation when patients and families are acutely emotionally burdened could lead to experiences of grief and death anxiety (Berlin et al., 2021). Thus, assessing preparedness for ACP in a valid and reliable manner can lead to EOL communication earlier in the illness trajectory. In summary, patient preparedness for ACP is a significant gap in ACP research.

The few existing instruments that have conceptualized preparedness as a behavioral change rather than a psychological and cognitive state, which prevents further studies and clinical practice from designing valid interventions to improve patient's preparedness and ACP outcomes. Existing instruments on preparedness often include items related to death attitude, trust, patient-clinical relationship, communication skills, and beliefs about ACP, which are the antecedents, rather than the attributes of preparedness. Using these tools may produce misleading results related to level of preparedness, factors influencing preparedness and classifications.

Preparedness has been characterized in prior research as a binary categorical ACP process outcome such that a person is either deemed prepared or is unprepared (Sudore et al., 2018). Yet, the conceptual process of ACP is a continuum and is moderated by an individual's perceptions, past ACP experiences and demographics. Inherent in the conceptual definition is a suggestion that psychological preparedness is a separate process outcome and attitude that co-exists with other developing death attitudes such as acceptance, awareness, and health related anxiety. Patient's perspectives and psychological readiness to initiate ACP has not been captured by existing instruments in research.

Another gap in previous studies includes lack of control of social desirability. The statements in the existing instruments often use value laden wording. Thus, to assess a patient's true level of preparedness, participants' responses should be adjusted for conscious and unconscious socially desirable responses. Controlling for social desirability can also help increase statistical validity of preparedness for ACP.

Significance of the Study to Nursing

Therefore, the significance of this research to nursing science is to identify the relationship among these related confounding variables and to explore the internal structure of the construct of preparedness. To improve advance planning completion rates, clinicians require objective process outcome measures of preparedness for ACP, readiness for EOL communication and completion of advance directives. A valid and reliable measure of preparedness requires study to determine the internal structure of the construct as well as validity and reliability testing of the proposed instrument. Assessment of predicting readiness for completing advance directives is lacking in current practice guidelines. A theory- based model that clarifies the contribution of psychological preparedness within the ACP process would be helpful to support nursing actions in EOL communication. Thus, the purpose of this study is to develop and validate an instrument to decipher and examine preparedness for ACP.

Chapter Summary

Worldwide initiatives have highlighted the importance of structured ACP programs to improve the psychological and financial impact of EoL on patients and the healthcare system. Despite legislation the uptake of advance directives is less than 50%. The IOM challenged health professionals to develop standards for ACP and EoL communication that are measurable, actionable, and evidence based. Advanced directive completion has been associated with intrapersonal factors including age over 75 years, higher education, income, and presence of more than 3 chronic diseases. Although evidence demonstrates improvement in the quality of EOL care, persistent gaps include challenges in the perceived educational readiness in nursing to care for and assess dying patients.

Readiness for ACP is prospectively different between patients, nurses, and health care providers. Current expert opinion recognizes psychological preparedness as a key construct for investigation and consideration in the ACP paradigm. Research has utilized the TTM to evaluate preparedness as a binary concept. However, ACP is a continuum and psychological preparedness is a separate outcome that co-exists with other developing death attitudes such as acceptance, awareness, and health related anxiety. Assessment of predicting readiness for ACP is lacking in current practice guidelines and NINR funded research. Nurses' perceptions of being prepared to deliver EOL care is associated with burnout and compassion fatigue. To improve EOL care, nurses require objective measures of preparedness. An assessment of patient's thoughts about ACP could aid nurses in providing quality EOL care.

Chapter II: Critical Review of the Literature

Conceptual Framework

The conceptual framework for this study is derived from several theories of psychological preparedness, review of the literature and Walczak et al. (2013) *model on discussion of prognosis and EoL*. The conceptual framework focuses on the relationship between preparedness, other factors influencing preparedness (e.g., uncertainty, awareness, acceptance, health anxiety) and the outcomes of ACP (Figure 1). In the theoretical framework, the outcomes of ACP include activities related to EoL communication, making advance care plans, and documentation of values, wishes and goals related to EoL care. Patient’s thinking about EoL, willingness, existential reflection and knowledge are key attributes of preparedness for ACP. Preparedness is the precursor for EoL communication and outcomes of the ACP process.

Literature supports a wide range of influencing factors for the development of preparedness including but not limited to (a) past experiences with ACP (b) an individual’s health status (c) one’s personal preferences, values and belief system, (d) religiosity (e) social supports, (f) health literacy, (g) uncertainty (h) decisional conflict (i) clinician experience (j) society/community influences (k) coping style (l) spirituality and (m) chronicity of illness (Alano et al., 2010; Bayer, Mallinger & Krishan, 2006; Campbell et al., 2007; Francke & Willems, 2005; Piers et al., 2013; Song & Sericka, 2006; Walczak et. al, 2013; Walczak et al., 2014).

Preparedness has been described as a process that may change in context with influences of moderating factors (e.g., prognosis, communication, and uncertainty). Yet, the complex nature of EoL decisions in the face of illness suggests preparedness is an iterative process. Preparedness can be influenced by interaction between the individual, the health care system, and the health care team in the form of facilitated communication that delivers prognosis and explores attitudes regarding EOL decisions. Preparedness results in the consequence of EOL communication of the patient’s values/preferences for EOL decisions and documentation of advance directives. Uncertainty, awareness, acceptance, and preparedness have complex interactions that are presently inadequately studied. Each of these interrelated but independent constructs are present in the proposed conceptual framework of this study: uncertainty, awareness, acceptance, and preparedness. Preparedness is iterative and exists on a continuum that reflects various degrees of wiliness for EOL communication and for various components of ACP.

Communication is an iterative process and occurs at multiple phases in patients with chronic illness. The Institute of Medicine (2014) suggests EOL communication should engage trust and be meaningful across the trajectory of chronic illness. Three forms of EOL communication occur during the trajectory of chronic illness; EOL preferences for life sustaining treatment; prognostication conversations and goals of care discussions (Bernacki et al., 2014; Levoy et al., 2020). The ability of a clinician to have skilled conversations and foster patient trust are modifying factors of readiness to have EOL communication (Walczak et al, 2016). Yet, clinician communication does not account for the factors that influence patient attitudes related to preparedness for ACP planning. In terms of this current study, routine communication and EOL communication are two separate concepts.

For the purpose of this study, preparedness for ACP is defined within the cognitive and affective dimension to explore intellectual, emotional, and psychological readiness to engage in EOL discussion and make arrangements and plans for EOL care. Awareness, acceptance, and fear of death interact with prognostic uncertainty in a complex manner as antecedents to preparedness. Preparedness is hypothesized as an iterative process that is influenced by intrapersonal and external factors. Preparedness can be modified by EOL communication to improve advanced directive completion rates.

The following section will discuss previous studies on the key elements in the theoretical framework. First, different perspectives and literature on ACP process will be addressed. Next, the concept of preparedness, theories of psychological preparedness and related literature will be analyzed. The last section in this chapter will evaluate research studies related to the antecedents (such as uncertainty, acceptance, and awareness) and consequences of preparedness (EOL communication and ACP outcomes).

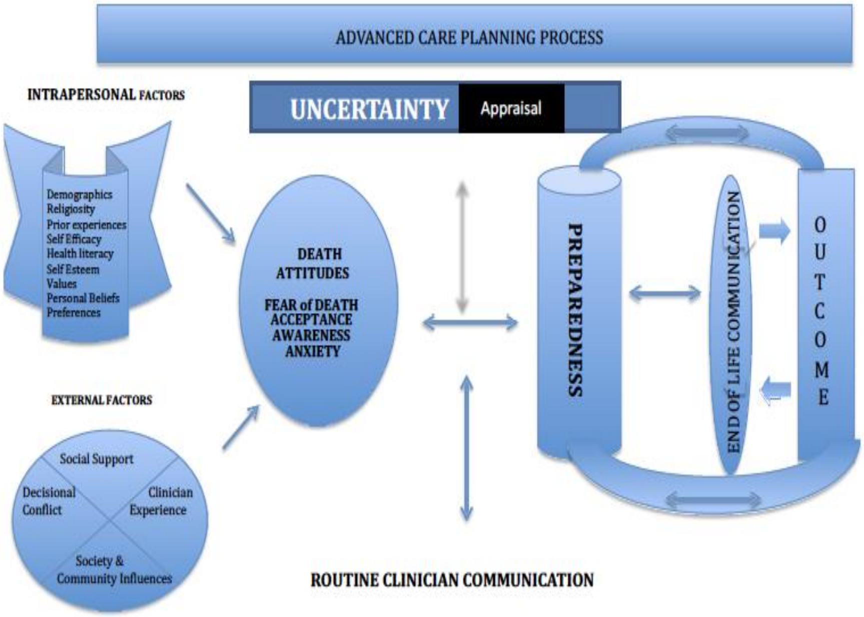


Figure 1: Visual of Advance Care Planning

Different Perspectives on the ACP Process

For the purpose of this study, ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness". This view is consistent with the Delphi study of a multidisciplinary expert panel, which reached an international consensus on the definition of ACP (Sudore et al., 2017). This is significant as up to 76% of patients will not be able to participate in at least a portion of decision-making regarding health care at EOL (Silveira, Kim & Langa 2010).

The expert panel also reached an agreement that ACP should focus on both discussion and documentation of planning for EOL care. ACP consists of three discreet activities: 1) patients thinking about life prolonging medical care 2) EOL communication of values and wishes for care, and 3) documentation of values and wishes for care including advance care plans and goals of care (Levi et al., 2010; Sudore et al., 2017). The comprehensive process of ACP includes thinking, communicating, and documenting for advance care planning (Bischoff et al., 2013). A growing body of literature has shown that relying solely on a written advance directive and arbitrary decisions about aggressive medical procedures does not adequately reflect patients' preferences and values for complex decision-making along a trajectory of chronic illness (Sudore & Fried, 2010; Heyland et al., 2013). Thus, ACP requires the development of preparedness for patients to engage in the comprehensive process.

In the theoretical framework for this study, the outcomes of ACP include activities related to EOL communication, making advance care plans, and documentation of values, wishes and goals related to EOL care. Patient's thinking about EOL is the antecedent of EOL discussion and the outcome, which is considered as part of the preparedness for ACP. Advance care planning requires the development of preparedness for patients to engage in the comprehensive process.

Results of other systematic reviews revealed ACP communication alone is also an insufficient attribute to prepare a patient completely psychologically for EOL decision making. Barnes et al. (2012) conducted a systematic review of the literature to identify all studies that evaluated or developed interventions related ACP communication with those who have life-limiting illnesses. The rationale for the study discussed that ACP communication in the absence of patient psychological preparedness for EOL communication may induce unwarranted anxiety. The study search strategy was exhaustive and inclusive of the United States, England, and Australia. The sample identified sixteen related quantitative and qualitative studies from a total of 755 articles that addressed clients with chronic illness with little awareness of death which hindered clinician ability to adequately prepare patients. Findings from two small sample size studies demonstrated that facilitated communication with a clinician trained in ACP discussions led to improved patient understanding, an increase in patient knowledge of ACP, satisfaction with the clinical decision-making process, improved quality of communication, and less decisional conflict with caregivers.

The patient perspective of readiness for EOL communication is willingness and desire to have knowledge about one's illness that reaches a threshold that overrides fear and ambivalence. Readiness results in an EOL discussion that allows patients to have further control in this framework. The key precursor to patients achieving readiness to discuss prognosis and EOL issues was theorized as adjustment and acceptance. Acceptance was being able to acknowledge EOL while still maintaining realistic hope as well as being able to accept uncertainty inherent in their disease trajectory and prognosis. The appraisal of uncertainty and acceptance of uncertainty has been studied extensively in literature. However, this study hypothesizes that uncertainty in chronic illness is an independent construct that is correlated with the outcomes of ACP. Preparedness requires existential thinking, coping with uncertainty after acceptance of one's illness.

Although international consensus by Sudore and colleagues (2017), emphasizes that preparedness for ACP should be assessed and the EOL communication should be tailored to individual's stage of readiness, it did not specify what strategies clinicians can use to improve patient's preparedness or what factors influence patient's preparedness. In contrast, the works by Walczak and colleagues tried to fill in this gap.

Walczak and colleague developed a *Model on Discussion of Prognosis and EOL* based on a qualitative study to explore patients' perspectives across Australian and American cultures regarding optimizing EOL discussions about prognosis and life sustaining treatments. Thematic analysis was utilized to interpret data obtained from qualitative interviews of 16 Australian and 11 American oncology patients (lung, prostate, bladder, and kidney) that were perceived to have 12 months of life remaining. Two global themes were identified, (1) readiness for and outcomes of discussions about prognosis and (2) end-of-life concerns. Thematic analysis identified two sub-themes regarding the antecedents to preparedness: acceptance and acknowledgment of impending death while maintaining hope and adjustment to uncertainty. Participants who reported readiness felt it necessary for discussions to achieve the best possible outcomes with the least discomfort. Two subthemes emerging from the data that constitute preparedness were a willingness to know overriding fear and ambiguity and a perception that the doctor is comfortable, confident, and able to discuss these issues. The study found that preparedness is a dynamic process in which multiple factors influence the wax and wane in preparedness.

Within Walczak's model, there are two independent processes that can lead to patient readiness for ACP, (1) communication skills of patients and their physicians or (2) patient adjustment to death and acceptance of uncertainty. They proposed three interrelated processes that can lead to patient readiness for ACP, (1) patient (and family) psychological adjustment to death and acceptance of uncertainty (2) mutual understanding between (family), healthcare provider and patient; and (3) a continuous, comfort and trust relationship with the healthcare provider.

However, results from a randomized control trial show the above strategies are not sufficient to improve patients' preparedness for ACP. Guided by their framework, Walczak and colleagues (2017) randomized advanced incurable oncology patients (N=110) to receive either a nurse led communication program (n=61) or standard care (n=49). Final analysis was performed on 40 control participants versus 39 intervention participants as there were a significant number of patients lost to follow up given the nature of terminal cancer. Multivariate analysis demonstrated patients and caregivers in the intervention arm asked more questions. However, contrary to the researcher's hypothesis, readiness for ACP communication was not improved by the intervention. This is because the framework and the intervention focused on clinicians' comfort and ease with EOL discussion. The framework also did not assess and tailor the communication to patient attitudes and preparedness for advance care planning.

Evolution of Preparedness for ACP

Pioneering psychiatric and psychological thanatological research influences the characteristics of preparedness within the context of ACP. Thanatology is the study of death and dying and the psychological mechanisms of dealing with approaching death. In the context of thanatology, preparedness often refers to death preparedness, an attitude toward death. Although there are conceptual overlaps between death preparedness and preparedness for ACP, these are two different concepts and play different roles in the ACP process. Death preparedness and related concepts, such as death awareness, acceptance and anxiety will be discussed in the "death attitude" section. A growing consensus recognizes that ACP is relevant to people in varying health states and should start as early as possible (Sudore et al., 2017; Hutchinson et al., 2017). Thus, the focus of preparedness for ACP is not on the incoming death or EOL, but on understanding and sharing personal values and preferences regarding future medical care decisions. Preparedness for ACP is a dynamic psychological and emotional state conducive to the initiation and continuation of EOL discussions and the readiness for advance care planning.

The concept of preparedness for ACP is rooted in psychological preparedness. In theories of psychological preparedness, in the context of hazards and sudden disaster research, preparedness refers to the "intra-individual and a psychological state of awareness, anticipation, and readiness capacity to anticipate and manage one's psychological response in an emergency situation" (Reser and Morrissey, 2009). Morrissey & Reser (2003) defined psychological preparedness as a process by which one overcomes the anticipation of an impending event. Similarly, in the context of disaster warning situation or a serious threatening event, the definition of psychological preparedness provided by Zulch (2019) is “heightened state of awareness, anticipation, and readiness for” (1) the uncertainty of expectation of a threat, (2) one’s psychological response to the threat and (3) ability to manage the situation.

Much like the appearance of a life limiting illness or trauma, a natural disaster is an infrequent occurrence that threatens one’s perceived control and existence. In the theory postulated by Morrissey et al. (2003), the reduction of perceived control caused by a threat activates defensive fear-control processes such as denial of risk, information-avoidance, and unwillingness to engage in anticipatory thinking activities (McLennan et al., 2014). The term psychological preparedness describes personal processes and capacity, including concern, anticipation, arousal, feeling, intention, decision-making and management of one’s thought feeling and actions (American Psychological Society, 2007). Once preparedness appears anticipatory thinking and information gathering can occur.

Given the definitions, psychological preparedness appears to involve several internal attributes including awareness, knowledge, anticipation, concern, thinking, feeling, experienced stress, motivation, intentions, readiness for decision making, management of, or coping with the threat (Reser & Morrisey, 2009; Malkina-Pykh & Pykh, 2013). Carroll (2010) also suggests that psychological preparedness involves motivation and an ability to anticipate and respond to uncertain future outcomes. Advance care planning involves reconciling the possibility of death due to chronic illness and therefore preparedness for ACP is a response to an expected or unexpected threat with varying degree of uncertainty.

Higher level of psychological preparedness can enhance an individual’s ability to appraise information, support decision-making and contribute to improved perception of control (Morrissey & Reser, 2003). There are similarities and differences between the anticipation of a disaster and the anticipation of the worsening of illness. Both disaster and human conditions are not always certain or predictable. Like disaster management, preparedness for ACP includes identifying thoughts and emotions that may exacerbate health related anxiety as well as developing coping strategies.

Gupta and colleagues (2016) suggest that psychological preparedness can create rational thinking in stressful situations and be utilized as a construct for life episodes, life stages and life events. Gupta (2016) suggests there are three sub-domains that contribute to the factors of psychological preparedness:

- “Awareness (knowledge) and anticipation of one’s own probable psychological responses to the uncertainty and stress of a disaster warning situation or event, including the ability to recognize stress-related thoughts and feelings. This domain includes an individual’s perception, appraisal, and understanding of the threatening event.
- Capacity, confidence, and competence to manage one’s psychological response to the unfolding situation or event, and to manage one’s social environment.
- Perceived knowledge and competence to manage one’s external physical situation and circumstances in the context of the situation”.

Etymological Definition of Preparedness

In English literature preparedness was first utilized in 1590 and is defined as the fact of being ready for something (Merriam-Webster Online Dictionary, 2019). The term “prepares” or “preparing” is defined as a transitive verb meaning (1) to make ready or plan prior to the purpose, use, activity, or event and (b) to put in a proper state of mind. Similarly, the term “preparedness” is defined as the quality or state of readiness in case of an event (Merriam-Webster Online Dictionary, 2019). Synonyms include readiness, willingness, inclination and to address (Oxford English Dictionary, 2017).

Definition of Preparedness for ACP

This study defines preparedness for ACP as the psychological and emotional state of willingness to engage in the process of ACP including EOL communication, medical decision- making and mental ability consider one’s past and present illness trajectory. Preparedness for ACP is a response to illness and includes existential reflection, thinking, knowledge and readiness to engage in EoL discussion and ability to manage and codify plans for EoL care. It is a prerequisite for EOL communication, and the outcome of preparedness is readiness to complete an advanced directive or designation of a health care proxy. Preparedness for ACP is preceded by attitudes of awareness and acceptance and is mediated by the uncertainty of illness and routine communication of illness delivered by a health professional.

Preparedness for ACP has been defined as the extent to which one is psychologically prepared to participate in informal ACP conversations and does not include signing formal documents. Wang & Sheng (2022) conceptualized three domains of preparedness: (1) attitude which refers to the psychological tendency to participate in ACP conversations contains subjective evaluation and acceptance. (2) Belief: refers to the confidence in the benefits of participating in informal ACP based on the judgement of personal values, which support an individual's participation in the process. (3) Motivation: refers to the internal drive that drives or impedes an individual's participation in ACP conversations.

Preparedness for ACP was featured by the degree of willingness and ability to consider personal relevance, to think about ACP related topics and future medical care decisions (Zwakman et. al., 2021). The level of readiness varies based on one's the ability to link thoughts to future scenarios related to EOL discussion and health care decisions, thinking about meaning of past life/illness experiences of family or friends, diagnostic understanding, prognostic understanding, and reflection on meaning in life.

Preparedness for ACP is an iterative as patients vacillated between readiness and not being ready because of EOL communication or changes in illness context and personal experiences. Synthesis of the findings defined preparedness for ACP as "the willingness and ability to engage in a discussion about the progression of one's illness one's current physical and/or mental state, one's preferences and wishes related to health care and medical decisions at the end of life, and possible future scenarios related to the end of life; one is also optimally ready for ACP when one can both rationally articulate one's stance toward end-of-life topics, can articulate one's corresponding emotions, and can imagine oneself in future situations." (Zwakman et al., 2021, p. 2925). Patients can be in various degree of preparedness and be prepared for different behaviors. A patient's level of preparedness for one behavior/topic is not always consistent with that for another behavior/topic. The following paragraphs will summarize literature related to the definition and attributes of preparedness for ACP.

Preparedness for ACP has been defined in terms of one's mental state and ability to discern medical choices and think about ACP. In a scoping literature review, ACP readiness from an elderly patient perspective was extracted from eight articles. The components that constitute preparedness for ACP include the mental ability to listen to medical professionals, the ability to organize information to ask questions, the desire to know and understand the benefits/risks of treatment and the willingness to communicate one's preferences and wishes

(Nakamura, 2019). Qualitative study in renal patients by Hutchinson et al. (2017) concluded that preparedness for ACP was value laden and individually relevant. They found that to be prepared for ACP, the patients had to think about ACP related topics, understand that ACP should not wait until they feel sick or unhealthy, and value the role of EoL discussion and ACP in their future health care and medical decisions. Many patients assumed their family knew their preferences and wishes and thus questioned the need to discuss ACP.

In contrast, to defining preparedness in terms of psychological thought, some researchers have conceptualized preparedness in terms the transtheoretical model of change (TTM). Readiness occurs in stages of change that are linear; precontemplation, contemplation, preparation, action, and maintenance. Based on the TTM, Fried et al. (2010) developed an algorithm to assess the different levels of preparedness for individual patients. Precontemplation occurs prior to considering a living will or discussion with loved ones about EoL preferences. Contemplation phase is when patients are thinking about a living will or discussion with loved ones about their EOL preferences in the next 6 months, while for the preparation phase, patients plan to carry out the above activities in the next 30 days. This algorithm simplified the goal of ACP to include two basic concepts that the older adults in the study were more likely to be familiar with. The study found participants can be in different stages for different behaviors (completing a living will vs. discussing quality and quantity of life). In addition, the stage for one behavior does not predict that for another behavior. These findings indicate EOL communication readiness was not the same as readiness for completing an advanced directive. This variation in stages of readiness leads to a confused concept in Sudore et al. (2015) where researchers discuss readiness for advanced directive completion as synonymous with readiness for EOL conversations.

Research related to TTM has used the theory to design patient engagement in the ACP process. In each of the studies using TTM, ACP behaviors varied with patients in different stages of readiness for the different ACP behaviors, without evidence of ordering or sequential completion. However, there is a significant lack of evidence and support for how to aid patients in moving through the stages (Fried et al., 2010). Perhaps, because the psychological state of readiness was not assessed before interventions were utilized to engage patients in ACP. The studies addressed completion of an AD after the process of engaging individuals in EOL discussions.

Attributes of Preparedness

Thinking & Troublesome Thoughts. Thinking about ACP related issues (e.g., current health status, life goals, values, and preferences for future medical care decisions, etc.) is an integral element in becoming prepared for ACP. However, research suggests that individuals do not spend sufficient time considering their wishes within a realistic framework of their health situation. Patients have reported not wanting to think about issues related to illness, death or dying (Fried, Bullock, Iannone & O'Leary, 2009; Schickendanz et al., 2009; Winzelberg, Hanson &Tulsky, 2005). Intrusive troublesome thoughts might provide for readiness by preparing already stored patterns of life events that alert an individual to danger and provide a coping response (Pierce, 2007). There has been limited research into the thinking component of ACP, perhaps since it is not readily measurable like discussions and documentation (Schickendanz et al., 2009).

Douglas & Brown (2002) explored patient's attitudes toward ADs and the completion of ACP documents. A convenience sample of thirty (30) hospitalized North Carolinian patients were interviewed by five general questions about ADs and an adapted Advance

Directive Attitude Survey (ADAS). The sample was representative of patients with chronic illness including cardiac, gastrointestinal, respiratory, oncology and cerebrovascular disorders. The ADAS, created by Nolan & Bruder (1997) is a 16-item survey that includes items to assess individuals' perceptions of an AD. Cronbach's alpha of the instrument is .74 with higher scores (range = 22 to 88) indicating more positive attitudes toward ADs. Participants in the study who scored higher than 65 completed ADs. Completion of an AD was reported by patients who desired to not have life support and who desired control over treatment decisions. This study was a small sample size. For example, the validation study of ADAS stated that 78% of participants thought having an AD would prevent caregiver guilt and 74% thought an advanced directive would decrease financial burden of medical expenses on family.

Zwakman et al. (2018) performed a systematic review of 3,555 articles of which twenty met the inclusion criteria to identify themes related to patient's thoughts and experiences in the ACP process. Readiness for ACP was identified as one of three feelings in addition to ambivalence and openness. Readiness for ACP was described as iterative as a necessary prerequisite to ACP but also as being promoted within the process of ACP. Troublesome thoughts and unpleasant feelings were invoked by the invitation to ACP and preceded EOL communication in eight of the cited studies. Being ready for EOL conversation was viewed as improving the unpleasant feelings. The appraisal of the troublesome thoughts and feeling ACP is stressful coincides with feeling not ready and is invoked by the mere invitation to participate in EOL conversation (Zwakman et al., 2018). Zwakman et al. (2021) conducted a secondary analysis of recordings from ACP conversations. Patients who expressed no worries or troublesome thoughts to treatments indicated basic readiness or willingness to engage in EOL communication. Therefore, research targeting thoughts and attitudes related to ACP is important to address in designing ACP interventions as they are an important barrier to AD completion.

Desire to know. Research regarding obtaining knowledge or wisdom demonstrates that achieving a cognitive sense of meaning in life is an important component of preparedness. This study defines preparedness for ACP as a cognitive desire to have facts (knowledge). Once the need for knowledge is met, barriers for ACP can be abated, and preparedness can occur.

Hong and colleagues (2017) postulate that knowledge about ACP may alleviate fear of death because it can awareness and enable individuals to consider possibilities related to EOL. In a secondary analysis of a cross-sectional cohort study, a sample of 2,026 Korean adults were surveyed regarding their knowledge about ACP. The scale developed consisted of a five item Likert scale assessing the level of knowledge about five components of EOL care plans: advance directives, death with dignity, hospice, last will, and organ donation. In predictive linear regression modeling, the strongest association was found between knowledge about EOL planning and death attitudes ($r = .26$, $p < .001$), followed by the association between life satisfaction and death attitudes ($r = .11$, $p < .001$). Interestingly, knowledge related to ACP had a stronger effect for those who had not experienced death of a family member or friend in the past year. Lack of knowledge related to ACP may demonstrate a stronger prediction of readiness than fear of death.

Empirical evidence supports that improved knowledge about ACP is also associated with reduced fear of death among health care professionals. Hegedus, Zana & Szabo (2008) designed a structured EOL communication course. The course was given to 127 health care professionals and 41 undergraduate medical students who completed the Multidimensional Fear of Death Scale (MFODS) on the first and last day of the course. The questionnaire is used to investigate forms of emotional reaction and subjective feelings in relation to fear of death. In the older age group (40+) significantly lower levels of Fear of the Dying Process (p = .007) and Fear of Premature Death (p = .009) factors were found. Although utilizing a convenience sample of future clinicians, knowledge abates fear of death.

Furthermore, prior studies suggested a potential interaction between preparedness and knowledge of ACP. Yonashiro-Cho, Cote, & Enguidanos (2016) conducted a grounded theory exploration of Asian-American attitudes and knowledge related to ACP. A key theme emerged regarding knowledge and preparedness for ACP. Participants demonstrated a confused knowledge regarding ACP. In fact, despite demonstrating a lack of objective knowledge some had participated in completing ADs. A second theme regarding EOL communication demonstrated that participants felt that they would be willing to receive knowledge regarding ACP only after a significant illness arose. This study demonstrated that individuals could be willing to complete ADs without definitive knowledge of ACP.

Studies support the relationship between knowledge, attitudes related to ACP and engagement of diverse populations in ACP. In a pre-test, post-test design, Heyman et al., (2010) found increased knowledge related to ACP improve Latino older adult perceptions related to ACP. In a mixed method pilot study conducted with 30 Southern African Americans, Huang et al. (2016) demonstrated increased knowledge in the RCT was associated with post intervention intent to complete ADs (t test = −3.06, *p* = .01, d = 1.67). This finding was also demonstrated in Asian Americans. Sun and colleagues (2016) significantly increased knowledge about ADs in a population of 148 Asian American church participants

(33.8 to 86.5 % p=.01). Intention to complete ADs and supportive ACP attitudes also increased.

Kermel-Schiffman & Werner (2017) conducted a systematic review of the literature on knowledge related to ACP and provided a description of the conceptual and methodological characteristics of the instruments used to assess knowledge regarding ACP. A total of 37 articles were included in the review. Six of the included studies were interventional studies of individuals without knowledge related to ACP aimed at improving ACP. In four of these studies a statistically significant difference was found between the intervention and control groups or pre-test and post-test (Gutheil & Heyman, 2005; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010; Murphy, Sweeney, & Chiriboga, 2000; Siegert & Kochersberger, 1996). In another two studies, there was no statistically significant difference found between the groups (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Song, Kirchhoff, Douglas, Ward, & Hammes, 2005). Knowledge regarding ACP was found to improve the likelihood of communicating about EOL. Conceptual differences in the ACP process and the types of knowledge imparted prevented a meta-analysis of these studies. However, the most common structured questionnaire assessing objective knowledge was the Knowledge, Attitudinal and Experiential Survey on Advance Directives (KAESAD), a 30- item true-false questionnaire developed originally to assess knowledge among professionals. No objective measures of measuring knowledge related to ACP in patients was found to exist.

Willingness. Psychological willingness has a direct association with attitude toward and completion of an AD. For example, Ko, Lee & Hong (2016) found willingness was significantly associated with attitudes towards ACP (t=2.26; p=.02). Odds of completing ADs increased 18% per point of the attitudes towards decision making. In a sample of 121 Korean participants, utilizing the Health Belief Model, a multiple linear regression demonstrated that perceived severity (B=.199, p=.021), perceived benefits (B=.221, p=.016) and cues to action (B=.159, p=.030) was associated with higher willingness to complete advance directives (Kim & Lee, 2021). Perceived barriers were associated with unwillingness (B= -.409, p < .001).

Willingness to complete ADs is influenced by health status and availability of a health care proxy. Ko and colleagues (2016) examined low-income older adults (n=204) who had not completed an AD. Older adult with prior and fair health status were more likely to complete than those with better health. Odds of willingness to complete ADs increased 1.43 times per level decrease in self-reported health. Older adults with healthcare proxies expressed a 73% willingness to complete ADs. Miyashita and colleagues (2020) also supported the association of willingness and health status in a mixed method study. More than 70% of patients in both Taiwan and Japan were willing to begin discussions and preparing for their EoL while not frail.

Willingness to participate in ACP is influenced by knowledge. In a Taiwanese cross-sectional quantitative survey design, Tsai, and colleagues (2022) evaluated willingness on a score of 0-10 by the measure “How willing are you to participate in ACP?” Higher scores indicated higher willingness. In a convenience sample of 198 adult outpatients, the average score was 6.19 with SD=2.85. Willingness to participate in ACP was associated with reduction of family EoL decision-making burden (OR=2.53). In participants that indicated ACP importance, 60% (n=85) demonstrated increased willingness. For example, health care professionals were 3.18 times more likely to participate in ACP (95% CI=1.25-6.28). A lack of knowledge was the main reason affecting unwillingness to participate in ACP (OR=.30, 95% CI =.14-.64). Qualitative research reports that prior experiences with EoL affect willingness for ACP. In a qualitative study, Fried et al. (2009) reported that viewing personal experiences of family and friends with EoL increased willingness to perform ACP. Similarly, Piers and colleagues (2013) synthesized that motivation for ACP was influenced by participant experiences with death and dying of a loved one. Moreover, personal experiences and fears were more relevant than topics initiated by healthcare providers.

Brown et al. (2017) developed and validated a scale to assess wiliness to engage in ACP among gynecology oncology. The Advance Care Planning Readiness Scale (ACPRS) is an eight-item scale with two subscales. In a study population of 110 women, five factors loaded on the concept of willingness to discuss EOL and three factors loaded on acceptance of EOL care. Associations between ACPRS score and completion of an AD revealed that women with prior ADs had higher ACPRS scores. For example, statistically significant results were seen among those with durable power of attorneys (p=.0030) and those with prior DNR orders (p=.0176). Convergent validity testing endorsed negative correlations of readiness when female patients had struggles with their illness contrary to prior studies (Mack et al., 2008) that had suggested male patients had positive correlations. Limitations of this study included the fact that it was restricted to female patients with gynecologic malignancy and did not examine a potential score that would indicate a patient’s readiness to discuss ACP.

Existential Reflection. An elusive component of preparedness for ACP is existential reflection. Preparedness requires an individual’s psyche to thoughtfully reflect on one’s mortality and quantity vs. quality of life to explore EOL decisions. Meaning of life as well as one’s assumptions regarding life and death are components of preparedness (Chan, Tin, and Wong; 2015). From an existential point of view, health related anxiety (e.g., fear of death) is universal and human beings living in a shared world are motivated to construct personal meaning in life (Frankl, 1984; Wong 2008, 2011). The perception that one’s life has meaning is considered the fundamental buffer against existential fear of death (Becker, 1973; Frankl, 1984). Thus, two basic psychological human tasks are defending oneself against fear of death (e.g., avoiding awareness of EOL) and self- actualizing a meaningful life (e.g., managing acceptance of EOL).

Oscillating intrusive thoughts are a complex strategy to prepare for stressful life events and lead to the formation of acceptance. Telford, Kralick & Koch (2005) describe shifting perspectives of acceptance when describing chronic illness that is applicable to preparedness. People in their experience of death are expected to transcend thru stages to achieve resolution of the conflicts invoked by a poor prognosis. Only then, when the person has come to terms with the new reality can they move forward. This movement does not occur in a single stage but rather in an oscillating movement of thought that may lead the individual to acknowledge, accept chronic life limitations and participate in an EoL plan (Haley, Allen & Kwak; 2011). Continual communication can aid in the patient’s acknowledgement of death and formalizing the EoL plan. This shifting perspective is consistent with the TTM of stages of change postulated by Fried et al. (2010) as a conceptual framework for ACP. Thus, an existential reflection is embedded within the construct of preparedness. However, as aforementioned shifting perspectives invalidates preparedness as a behavior and affirms the concept as an attitude.

Existential reflection is also a consequence of nursing presence. Nursing presence is an intersubjective encounter between a unique nurse and a unique patient in each one's universal human solitary experience (Doona, Haggerty & Chase, 1997). In nursing practice, nurse theorist Rosemary Parse conceptualized reflection as a phenomenon that all humankind experience (Parse, 2010). The Parse theory is a framework of “being present” that can aid nurses in facilitating patients’ transition from denial to acceptance. Because death is truly a universal human experience, nurses are privileged to witness their patients’ acceptance during EOL care and be invited by the patient to travel with them during the experience. Within the framework of a trusting nurse-patient relationship, nurses assist patients with existential reflection related to their EOL decisions and goals.

Fried et al. (2009) utilized grounded theory to explore preparedness among elderly populations with the outcome of ADs. A key probe relative to preparedness science was “What kind of planning do you think you should be doing to prepare for the possibility of developing a serious illness?” The study illustrated that the variable of patient preparedness to engage in ACP suggests that the most effective method to increase the quality of ACP would be to provide patient-centered interventions, based upon an individualized assessment of a person's willingness to change and engage in EOL discussion. Therefore, education about completing ADs is insufficient to change the behavior of an older person who finds it difficult to contemplate death and dying. Instead, a more effective intervention is to acknowledge the shifting patient perspectives related to death attitudes involved in the process of becoming prepared for ACP. Therefore, an important attribute of preparedness is the psychological willingness that results from the positive transition of death attitudes acceptance and fear of death to readiness for EOL communication.

Existing Instruments to Assess Preparedness for ACP

Sudore et al. (2013) further explored completion of ADs as a gold standard of the ACP outcome. Sudore at al. (2013) developed and validated “The Advance Care Planning Engagement Survey”. The Advance Care Planning Engagement Survey scale is an 82- item measure to assess four ACP behavior changes (knowledge, contemplation, self-efficacy, and readiness) within four ACP domains that affect behaviors (i.e., surrogate decision makers, values and quality of life, flexibility for surrogate decision making, and informed decision making). In a single setting of 50 participants with an average age of 69.3, the four ACP behavior measures (knowledge, contemplation, self-efficacy, and readiness) demonstrated adequate reliability with a Cronbach's α =.93. Readiness was assessed by asking how ready participants were to ask questions, talk about decisions and sign ADs. The four ACP domain measures were assessed by test-retest and demonstrated intra-class correlation, .87. Advanced directive completion was not assessed. Moreover, thoughts, reflection and knowledge related to illness were not part of the framework.

One great benefit of both the work of Fried et al. (2010) and Sudore et al. (2014) is the ability to classify specific ACP behavior change stages, such as pre-contemplation, contemplation, preparation, action, and maintenance. However, completion of an AD is not conceptualized by their research. Conceptualizing preparedness as a behavior of change rather than an attitude omits the perspective that maintenance and relapse prevention in the context of ACP does not exist. Patients can change their initial decision when reflecting on thoughts and be perceived as being "unsuccessful" at ACP.

Grounded theory has been utilized in the literature to identify preparedness for EOL discussions in patients without primary exposure to ACP. Calvin (2004) proposed a theoretical framework to explain the behaviors of hemodialysis patients in completing and planning their ADs. Based on the theory, Calvin & Erikson (2005) developed the Advance Care Planning Readiness Instrument (ACPRI) to assess the attitudes of renal patients' relationship to personal preservation and their readiness to discuss ADs. The goal of the

ACPRI was envisioned to aid clinicians in determining an individual patient's readiness (i.e., preparedness) for advance planning communication (Calvin et al., 2005). The research produced an instrument with a content validity index of .90 and internal reliability consistency coefficient of .73. The instrument, although designed for and piloted with renal patients, contains items applicable to preparedness for ACP in any population. Yet, larger studies to validate the initial findings were never conducted (Calvin, 2015, personal communication).

Von Blanckenburg, Leppin, Nagelschmidt, Seifart, & Rief (2021) alluded to the TTM in their study regarding readiness to engage in EOL. Utilizing EOL motivational interviewing, researchers engaged participants to have existential reflection on their values. Older individuals demonstrated a higher readiness for EOL plans. Moreover, in the study of 269 participants, psychological constructs demonstrated acceptance and thinking about existential awareness of dying (reflection) explained a portion of readiness (preparedness). The constructs of Von Blackenburg et al. (2021) were like this proposed study including the primary outcome of readiness to engage in EOL communication and the secondary outcomes of fear of death, death acceptance and fear of dying. In a sub analysis of a RCT of palliative patients in Germany, 269 participants were randomized to either receive ACP motivational communication or general health topics. Measurement tools included the *Readiness to Engage in End-of-Life Topics* (Cronbach's α =.86), *Multidimensional Orientation Toward Dying and Death Inventory* (Cronbach's α =.82 to .92) and the *Patient Health Questionnaire PHQ-9* (Cronbach's α =.89). Demographic data included age, education, gender, marital status, religiosity, chronic disease, and the presence of traumatic life events. Analysis of covariance was performed to control for demographic variables and a mixed 4x3 ANOVA within and between factors was conducted for the dependent variable of readiness. Individuals who did not engage in EOL communication as evidenced by dropping out of the study had statistically significant rates of higher fear of death (F [1,191] = 21.90, p <.001) and fear of dying (F [1,191] = 1.45, p <.001) and lower values of death acceptance (F [1,191] = 11.00, p <.001). In addition, the intervention group had increased readiness than the control group as well as higher rates of death acceptance as the intervention progressed over time. The study could not find a group effect on fear of death and death acceptance which was contrary to sentinel psychologic research and suggested that the missing variables of death anxiety and awareness were not completely conceptualized. This proposed study conceptualizes that awareness and acceptance may be the elusive precursors of readiness for EOL communication.

Berlin et al. (2021) developed an instrument to assess readiness for EOL communication. In an exploratory factor analysis, a 13-item measure entitled the *Readiness for End-of-Life Conversations (REOLC)* Scale was created based on the Transtheoretical Model of Change. Three domains were included; (1) readiness to engage in end-of-life thoughts and conversations (2) knowledge about personal barriers, facilitators, and topics to discuss and (3) congruence between values and life before and during palliative treatment (importance of values). A community sample of 349 German participants aged 18 to 88 years were included. The exploratory factor analysis resulted in three subscales: readiness (Cronbach α = .84), communication (Cronbach α = .76), and values (Cronbach α = .56) for a community sample. In subsequent divergent validity testing, the REOLC scales was tested with psychological distress measured by the distress thermometer and death anxiety measured by the German version of the Death and Dying Distress Scale (DADDS-G; Cronbach α = .90). A sample of 84 cancer patients were utilized and in structural equation modeling the three-factor solution with 13 items was not supported for cancer patients. Factor structure was adapted to 12 items with one common factor readiness (Cronbach α = .87). For the REOLC scale items rated highest were “I have already learned a lot about life”, “I am aware of what in life is important to me”, and “I believe that dealing with the end of life is part of life. The internal consistency of the entire scale was acceptable (Cronbach α = .86, CI [.81; .90]). In criterion validity the scale no significant correlations with general anxiety, fear of recurrence, death anxiety, distress, and depression.

Confirmatory factor analysis of the REOLC did not support the conceptualized three domains. Readiness in this study did correlate for gratitude. The scores had a weak relationship with completion of a living will or talk with family about the end of life. Limitations of this study included a small cancer population during divergent and criterion validity testing which may account for lack of correlation to anxiety and fear. Furthermore, the low scale performance on values and lack of correlation to attitudes highlights that this scale may objectively measure readiness for EOL conversations but incompletely captures values and attitudes necessary to discern preparedness for ACP. Berlin et al. (2021) translated their instrument into English for publication so cross-cultural validity has not been evaluated in American populations. Their research suggests that attitudes and values related to EOL are important to capture to prepare one for ACP.

In Asian culture, readiness instruments for ACP focus on the relational aspect of patients and families. Sakai and colleagues (2022) developed the *Readiness for Advance Care Planning Scale* (RACP) in Japan. The 28-item instrument based on the TTM has five subscales; recognize the importance of talking and writing, intend to talk, intend to write, preparations for the behavior, and practice of talking and writing. Cronbach’s α for the overall scale was .95 and the subscales ranged from .90 -.97. The instrument assesses the level of readiness for ACP behaviors but does not account for the psychological state of readiness.

Similarly, the Advance Care Planning Readiness Questionnaire was validated in a community sample in Peking China. Wang et al., (2022) developed a 22-item questionnaire with three domains: attitude (10 items), belief (7 items) and motivation (5 items). Cronbach's α for the overall scale was .92 and the subscales ranged from .83 -.90. The ACP readiness score ranged from 22-110 and was divided into four levels. In a community sample of 168 adult participants with chronic disease, ACP readiness was associated with longer duration of disease, higher income, previous EOL experience and active coping styles. Cross cultural validity is difficult in Western culture as the medical-legal system differs and legislation affects perception of advance directives.

In summary, research regarding preparedness is significantly lacking in rigor and homogeneity. Many studies have utilized the TTM or HBM framework which conceptualizes preparation for completing an advanced directive. Thus, there is a lack of a comprehensive and valid instrument to measure preparedness for ACP. Current scales have been developed in Eastern and German cultures which would require cross cultural validation. Moreover, literature that examines readiness for ACP is scarce. Preparedness as proposed by this study is a psychological attitude that has four attributes: thinking/troublesome thoughts, willingness, knowledge (desire to know) and existential reflection. By assessing preparedness for ACP, EOL communication can be designed and tailored to the patient level of preparedness. However, there is still a gap in literature exploring preparedness and ACP influencing factors of uncertainty and death attitudes.

Uncertainty: Definition and the role of Uncertainty in ACP

Uncertainty about perceived life expectancy and prognosis during chronic illness has been conceptualized in Mishel Theories of Uncertainty (Mishel & Brayden, 1987; 1988; Mishel, 1999; Mishel & Clayton, 2008). The uncertainty theory attempts to conceptualize how a patient's cognitively process and give meaning to illness. In 1990, Mishel reconceptualized her theory to address the iterative nature of uncertainty in advanced chronic illness. The uncertainty theory conceptualizes how patients when faced with acute or chronic illness cognitively processes illness and/or impending death. Mishel defines uncertainty as the "inability to determine the meaning of illness" mainly due to the inability to accurately predict outcomes because sufficient cues are lacking (Mishel 1988; 1990). In this reconceptualization, the appraisal of illness meaning is not static but is a process that perceives uncertainty as fluctuating over time.

Mishel (1990) reports psychological theories of uncertainty pay minimal attention toward irreversible processes within the environment. Within the confines of advanced chronic illness, uncertainty is a complex construct that may involve multiple concerns not limited to the severity of illness, treatment impact, as well as the impact of illness on one's life, hopes and dreams. Uncertainty in the reconceptualization is not a binary emotional response but rather a fluid cognitive state that expands over a continuum of change (Clayton, Dean & Mishel, 2018). Uncertainty exists when situations are ambiguous, unpredictable, or probabilistic and when knowledge is unavailable or inconsistent (Babrow, Hines, & Kasch, 2000). The cognitive appraisal of uncertainty occurs when a severe and unpredictable illness-related event with unforeseen consequences occurs, thereby creating an iterative appraisal of the illness state as a danger or an opportunity (Bora & Buldukoğlu, 2020; Clayton et al., 2018). Within the appraisal of uncertainty, two evaluative measures are utilized: "inference" and "illusion". Inference is the evaluation of uncertainty based on related past experiences, knowledge, or cultural disposition. If inferences are positive, then uncertainty is considered an “opportunity”. However, if inferences are perceived as threatening or fears, then uncertainty is considered a “danger”. Illusions are constructed protective beliefs. Illusion allows uncertainty to be considered a potential sign of hope for a positive outcome. Due to the indefinite and flexible nature of uncertainty, events that are prolonged can be rearranged as an illusion indicating a positive situation. Thus, the impact of uncertainty on preparedness for ACP may vary depending on if uncertainty results in positive or negative feelings (Zwakman, 2018).

Crucial key components of Mishel (1990) reconceptualization of uncertainty were the introduction of the appearance of “self-organization” and “probabilistic thinking” as an adaptation to uncertainty. Self-organization refers to the acceptance of continuous uncertainty as a new understanding of chronic illness. Probabilistic thinking refers to the belief that everything in life cannot be sure and results of the illness experience cannot be foreseen. A curvilinear relationship exists between uncertainty and probability such that when the probability of an event is known and certain; uncertainty is nil (Brashers, 2001).

The key elements of uncertainty as it pertains to this study include cognitive appraisal of information about illness, patients’ ability to make sense of prognostic information and their potential to use that information to take an active part in decision-making. The reconceptualization of uncertainty suggests strategies that improve knowledge about disease, cognitive reframing, problem-solving and communication skills can manage uncertainty, and thus enhance preparedness (Bora et al., 2020). This supports the view that appraisals of uncertainty as hope or danger may influence an individual’s preparedness for ACP (Brashers, 2001). Research related to chronic illness has suggested that uncertainty consists of four attributes: ambiguity, unpredictable symptoms, or outcomes, inconsistent or inadequate information regarding the medical condition or treatment, and unclear meaning (Sharkey et al., 2019). Psychological and emotional response to the appraisal occur to manage uncertainty.

Uncertainty as an antecedent to preparedness requires individuals to determine meaning from appraising their perception of chronic illness and mortality. As an individual appraises their mortality and manages their uncertainty, they change their preparedness for ACP. This hypothesis is consistent with aspects of prior EOL communication research that has supported Mishel's Uncertainty in illness theory (Brashers, 2001; Hines; 2001). Uncertainties are related to the illness but also to the desirability versus the undesirability of the outcomes of the decisions the illness invokes.

Uncertainty and Communication

Communication science researchers, informed by previous studies and theories, have linked communication and uncertainty within the Uncertainty Management Theory (UMT), which explains the relationship between the experience of uncertainty, appraisal, behavioral and psychological responses to uncertainty (Brashers, 2001). The UMT postulated that because uncertainty is multilayered, interconnected and temporal, individual's response to and strategies to manage uncertainty may vary across different contexts and situations. Affective and emotional responses arise from uncertainty appraisal. The opportunity and threat appraisals are associated with positive and negative emotional responses. Uncertainty appraisal can also lead to neutral (being indifference or inconsequential) and combined emotional responses (co-occurrence of negative and positive emotional responses). Individuals can employ different strategies to manage uncertainty, which include (1) seeking or avoiding information; (2) adapting to uncertainty; (3) obtaining assistance with uncertainty management; and (4) managing uncertainty management.

Hines (2001) related UMT to ACP to better understand individual's EOL treatment preferences and EOL decisions. Consistent with Brasher's view that uncertainties are multilayered and interconnected, Hines theorizes three forms of interrelated uncertainties. Uncertainties are produced when communicating medical information, risks, benefits, and chances of survival. Uncertainties are related to the effects of illness but also to the outcomes of possible coping strategies and the desirability versus the undesirability of the outcomes of the decisions the illness invokes. A failure to understand the forms of an individual's uncertainty, or the interrelated nature of different forms of uncertainty, may compromise the efforts of EOL communication. Communication within the paradigm of uncertainty may be a source of uncertainty (e.g., a patient attempting to understand clinicians' medical jargon) or play a central role as a coping strategy to mitigate uncertainty (e.g., hopeful messages can invoke comfort at EOL).

Hines (2001) expanded Brasher's perspective on responses to uncertainty and hypothesized that individuals will be less likely to use certain strategies to manage uncertainty if they believe the efforts will increase uncertainties about more important issues. Other factors that influence an individual's use of certain strategies to manage uncertainty include the expected outcomes of uncertainty management, the coping strategies used by others and past use of similar strategies. Hines also challenged the traditional view that EOL communication can reduce uncertainty, or it is favorable to reduce uncertainty through documentation (such as an AD, DNR order, power of attorney, etc.), which may force an individual to face a series of frightening, confusing and unsolvable medical contingencies. Instead, ACP should address a broader range of more manageable uncertainties. Hines' approach to uncertainty management emphasizes the importance of patient's preparedness and factors that are sensitive to the needs of patients and their families.

Given the temporal nature of uncertainty, a growing body of literature recommends that EOL communication is ongoing and should be revisited as context and situation changes (Hines, 2001; Walczak, et al. 2013; Sudore et al., 2017; Zwakman et al., 2021). Uncertainty was a barrier for ACP even when death was expected. Prognostic uncertainty in the context of elders greater than 90 years of age make determining hospital admission challenging. Participants reported desiring EOL communication related to ACP so that they could become prepared. In addition, the forms and meaning of uncertainty may shift across different stages of illness. Thus, it is important to assess the varied levels of preparedness for ACP over time and tailor EOL communication to address different forms and meanings of uncertainty.

Given the complex relationships among levels of uncertainty, emotional responses to uncertainty, uncertainty management and communication, research findings are inconsistent when only uncertainty and communication were studies. Findings from cross-sectional observational studies often report uncertainty as a barrier to ACP. Killackey, Peter, MacIver, & Mohammed (2019) conducted a narrative synthesis of 43 articles related to ACP in heart failure patients, which found uncertainty about diagnosis, prognoses or illness is a patient identified key contributor to avoiding or delaying EOL communication. Knowledge deficits related uncertainty about one's prognosis or illness and healthcare choices due to has been as a barrier to ACP in other patient groups (Banner et al., 2019; Schickedanz et al., 2009; Taneja et al., 2019). Community dwelling participants echoed lack of knowledge related uncertainty as a barrier to ACP engagement (Taneja et al., 2019; Banner et al., 2019), as one participant explained, "It is all very confusing. It is not that I don't want to think about it, in terms of dying or death, that does not bother me. It is just too confusing" (Banner et al., 2019, p.217).

Findings from a longitudinal cohort study did not support the relationship between uncertainty and ACP engagement. Tang et al. (2019) explored longitudinal changes in life sustaining treatment preferences and their associations with accurate prognostic awareness, physician-patient EOL communication and uncertainty regarding treatment preferences. The results found uncertainty about treatment preferences does not have an association with physician-patient EOL communication or accurate prognostic awareness to conduct EOL communication. These findings indicate the level of uncertainty about treatment preference is independent from accurate understanding about prognosis. In addition, there might be a complex relationship between uncertainty and EOL communication, or another variable (such as emotional response to uncertainty or uncertainty management strategies) may moderate the relationship between uncertainty and EOL communication.

Relatively few empirical studies have examined the role of appraisal in UMT. To this end, a study using experimental design in a laboratory setting has explored the relationship among uncertainty, appraisal and information seeking behavior (Rains & Tukachinsky, 2015). College students (N=157) were primed to feel and desire more or less uncertainty about skin cancer. Actual and desired skin cancer uncertainty, appraisal intensity and information-seeking depth were measured. Structural Equational Modeling results showed the desired level of uncertainty, but not the actual level of uncertainty, moderates the relationship between appraisal intensity and information seeking activity. One unexpected finding is when uncertainty was appraised as an opportunity, information seeking depth (spending greater time per webpage but visiting fewer pages) increased. The author explained that the different appraisal outcomes lead to different motivation for seeking information. Participants who appraised uncertainty as danger tried to mitigate the threat by searching widely and shallowly to disconfirm their existing knowledge and assuage the negative emotion. In contrast, participants who believed uncertainty was an opportunity took more time on each webpage attempting to confirm their existing knowledge and thus maintain the positive motion response. These findings have significant implication to preparedness for ACP. To help individuals become prepared for ACP, healthcare providers should assess the actual tolerable level of uncertainty and tailor communication to individual patients' needs.

In sum, despite the clear depiction of uncertainty appraisal in Mishel and Brasher's theories, more research studies are needed to examine the role of uncertainty appraisal in preparedness for ACP.

***Prognostic Uncertainty*/Awareness**

Prognostic uncertainty as an unknown probability of treatment success contributes to patient's inability to assign a value to their illness or accurately predict future outcomes. Gramling et al. (2018) conducted a multisite observational cohort study entitled the Palliative Care Communication Research Initiative. The study enrolled 236 hospitalized patients with advanced cancer into an inpatient palliative care consultation intervention. A Likert scale of the single question that enquired measured prognostic uncertainty; "over the past two days, how much have you been bothered by uncertainty about what to expect from the course of your illness?" Prognostic uncertainty was moderately bothersome for 75% of the sample. A key limitation of this study was construct specificity of prognostic uncertainty as a single item measure lacks precision and sensitivity.

Verduzco-Aguirre et al. (2021) performed a secondary analysis of baseline data from an RCT (N=541 patients) that evaluated communication and uncertainty in geriatric cancer patients. Uncertainty measured by a modified nine item Mishel Uncertainty in Illness Scale (MUIS) (Cronbach's alpha =.72) was the independent variable. Using the MUIS modified scale, 23.6% of participants agreed or strongly agreed that "explanations I've heard about what to expect for the course of my illness seem hazy to me". Additionally, 70% of participants agreed or strongly agreed that "the seriousness of my prognosis has been determined" and 74% understood "everything explained" to them. Researchers suggested uncertainty and awareness could be improved by communication. The researchers suggested that patient's attitudes, including positive appraisal of prognostic uncertainty, lead to hope. This suggests that reducing prognostic uncertainty requires assessment of patient's psychological state. Communication as a strategy can improve prognostic awareness but prognostic uncertainty requires cognitive reframing. Preparedness as a concept occurs after cognitive reframing of prognostic uncertainty and coping management of the troublesome thoughts invoked by routine conversations.

Prognostic uncertainty has been considered a barrier in patients who have surpassed their life expectancy. Krawczyk & Gallagher (2016) conducted a grounded theory exploration of communication with caregivers to improve prognostic uncertainty. Although the specific patient's view was missing due to their death, caregiver surrogates expressed lack of prognostic awareness led to feelings of being unprepared. A secondary theme emerged that prognostic uncertainty was not resolved until the patient was imminently dying leading to missed opportunities for preparedness for ACP. Fleming and colleagues (2016) suggested that uncertainty was a barrier for ACP even when death was expected. Prognostic uncertainty in the context of elders greater than 90 years of age make determining hospital admission challenging. Participants reported desiring EOL communication related to ACP so that they could become prepared.

Song et al. (2015) conducted a RCT involving a sample of 210 dyads of dialysis patients and their surrogates. The interventional study used a standardized ACP approach entitled, *Sharing Patient's Illness Representation to Increase Trust* (SPIRIT). The communication intervention followed a determination of the patient's prognostic awareness and the patient's understanding of diagnosis. The SPIRIT communication sessions attempted to address the cognitive, emotional, and spiritual uncertainties of the patient. The pilot study evaluated preparedness as an outcome measure for renal patients and their surrogates. Longitudinal data measurements at 2, 6, and 12 months were conducted, and later surrogate bereavement data was obtained at baseline, 2 weeks and 3 and 6 months after patient death. Coercion was potentially introduced by monetary compensation that ranged from fifteen to thirty dollars each time a survey was completed. Preparedness was measured by the 13 item Decisional Conflict Scale (DCS, Song et al., 2006). Patient decisional conflict decreased over time with the SPIRIT ACP intervention based on cognitive prognostic awareness (*B*=.13; 95%CI=.01,.24; p=.03). This study confers that ACP interventions that address cognitive attitudes and prognostic awareness longitudinally are superior to usual care.

Song et al. (2015) although addressing prognostic awareness did not actually measure the construct of preparedness that is proposed by this study. The DCS measures an individual's personal uncertainty in making a choice among healthcare options, perceptions of modifiable factors contributing to the uncertainty, and the perception of the quality of the decision-making process and the decision made (Song et al, 2006). Thus, the DCS consists of three subscales: uncertainty (Items 1–3); the main modifiable factors contributing to uncertainty, such as feeling uninformed (Items 4–6); feeling unclear about one's values (Items

7–9); feeling unsupported in the decision making (Items 10–12); perception of the effectiveness of the decision making after the decision is made (Items 13–16). In terms of the preparedness as proposed in this study, decisional conflict does not measure unmodifiable attitudes related to preparedness such as troublesome internal thinking and prognostic uncertainty.

In summary, the relationship between appraisal of uncertainty, prognostic awareness and preparedness for ACP is limited in research study. Cognitive appraisal and reframing of prognostic uncertainty may have a role in coping with psychological death attitudes. The extent to which uncertainty in chronic illness is related to preparedness for ACP has yet to be studied. This study proposes that uncertainty appraisal has a role in modifying death attitudes.

Death Attitudes

Throughout the 1970s and 1980's, most empirical research of death attitudes focused on fear of death, death avoidance and death anxiety. The work of Kubler-Ross (1969) that defined the stages of dying factored heavily into research in these decades. Several instruments were developed to assess fear of death, awareness, and acceptance as individual constructs (e.g., Collett & Lester, 1969; Folkman & Lazarus, 1980; Hooper & Spilka, 1970; Neimeyer, Dingemans, & Epting, 1977). However, the interrelated nature of the pursuit of personal meaning to the death attitudes of acceptance and fear was not explored until the late 1980s by Gesser, Wong & Reker (1987), at the height of the acquired immunodeficiency (AIDS) epidemic.

Gesser, Wong & Reker (1987) concerned their work with the psychological preparedness of healthy individuals when faced with the prospect of personal demise. They postulated that death acceptance could occur before terminal illness diagnosis and therefore individuals could bypass the stages of grief as theorized by Kubler-Ross (1969). Crucial to the conceptualization of preparedness is to understand the social context of the thanatology research in the late 1980's that equated death acceptance as a coping response synonymous to psychological preparation. In 1987, HIV infection was the 15th leading cause of death replacing congenital anomalies with a death rate in the U.S population of 11.5 deaths occurred per 100,000 resident population. Prior to protease inhibitors, in 1995, HIV was the leading cause of death for those aged 25 to 44 years and overall accounted for 32.6 deaths per 100,000 residents occurred in the United States. Kubler-Ross (1987) extended her theory of adjustment to terminal illness in AIDS research. Realistic acceptance was characterized as a psychological state and adaptive response allowing individuals to make final preparations (Reed et al., 1994). Reed et al. (1994) measured the subscale of realistic acceptance by an adaptation of the Lazarus's Ways of Coping Scale. Realistic acceptance correlated positively with coping. However, Reed et al. (1994) conceded that this work did not refine understanding of a key item component; "prepare myself for the worst". Griffin & Rabkin (1998) in a study of 42 NYC residents with AIDS demonstrated that realistic acceptance was associated with more comprehensive ACP. Participants who completed a will or assigned a health care proxy had statistically significant ($p < .05$) higher acceptance scores than their counterparts who did not. Yet, the study did not explain the psychological component of preparedness that precedes the completion of advance care plans.

The work of Kubler-Ross (2005) investigated death acceptance as an adaptive death attitude that facilitated planning for the end of life. Preparedness was a resignation to the prospect of death and involved the physical aspects of preparing for death (e.g., preparing a will and funeral arrangements). The aforementioned studies that equated death acceptance and preparedness as a method of coping viewed death at the very end of life. This empirical conceptualization of acceptance as synonymous with preparedness is difficult to reconcile with the preparedness in this study as former researchers postulated preparedness as preceding acceptance. Yet in the context of advance planning, one can mentally prepare for death prior to a terminal condition and without death acceptance.

Dame Cicely Saunders, the founder of the first modern hospice and the culture of palliative care, first suggested that patients should be informed truthfully about their diagnosis and prognosis to improve acceptance (Saunders, 1959). Saunders, who received her original training as a nurse in the Nightingale School of Nursing, later became a social worker and physician. In 1967, she founded the first purpose-built hospice, St. Christopher's Hospice. While engaged in clinical practice, she established both teaching and clinical research centers to promote palliative care and improve care among the dying. Saunders (1978) affirmed that facing death is an individual process. Moreover, a clinician's ability to recognize an individual's uniqueness aids the individual's ability to complete their life's journey (Saunders, 1993). In summary, Saunders postulated that death is a journey that occurs after acceptance, self- awareness, and reflection of life's meaning. In originating the movement of palliative care, Dame Cicely Saunders, started a global dialogue about planning for care at end of life. Palliative care, in addition to relieving pain and physical symptoms of illness, focuses on the existential meaning of life, including an individual's emotions, thoughts and behaviors. Thanatology and research regarding death attitudes are significant to palliative care to enhance psychological well- being.

In the new millennium, social cognitive theory and global terrorism influenced ontological understanding of the term preparedness for this study. Neimeyer, Wittowski &

Moser (2004) suggests that the tremendous exposure to death and grief in the aftermath of the World Trade Center terrorist attack led to an increase in public conscious thoughts of death awareness and particularly death anxiety. Yet, consistent with the existential writings of Ernest Becker, when faced with death unconsciously, people invest heavily in their conscious beliefs to defend against thoughts of death but embark on psychological readiness (Burke et al., 2010). End of life attitudes (e.g., fear of dying) co-exist with personal reasons (e.g., finding time to complete ACP paperwork) and were found to be important barriers for ACP (Fried et al., 2009).

The relationships among prognostic awareness, preparedness for ACP, EOL communication and ACP outcomes are complex. Chen et al. (2019) conducted a RCT of 460 dyads of terminally ill cancer patients and their caregivers in Taiwan. The intervention was guided by the Transtheoretical Model (TTM), which include 4 components: (1) repeated assessments of preparedness for ACP; (2) tailored intervention based on stages of preparedness for ACP; (3) facilitated communication regarding prognosis and EOL care; and (4) a booklet and a video to improve knowledge about ACP and life sustaining treatment (LST). The study found the intervention significantly improved prognostic disclosure as compared to the control group [OR = 1.60, 95% CI: (1.13 – 2.26)]. This practice is somehow different from that in the U.S. because of cultural differences. Participants in Chen's study were asked if they wished their healthcare providers to disclose their prognostic information. Another important finding is that prognostic awareness modified the relationship between intervention group and receiving CPR in the last month of life. Compared to patients in the control group without accurate prognostic awareness, patients in the intervention group with accurate prognostic awareness were 84% less likely to receive CPR (OR = 1.60, 95% CI: 1.03

– 1.73). Among patients without accurate prognostic awareness, utilization of LST in the last month of life did not differ between intervention and control groups. A major limitation of this study was that the ACP outcome was measured by use of LST during EOL rather than the percentage of LST consistent with patient’s wishes. Although the researchers described that preparedness for ACP was assessed in the intervention group, it is not clear what tool was used and how participants were classified into the 5 stages of preparedness. As a result, the study did not report if preparedness for ACP was improved after the tailored intervention and if the improved preparedness made EOL discussion easier.

Prognostic Awareness

Prognostic awareness has a temporal aspect and changes along the trajectory of EOL, which affects a patient’s acceptance of prognosis. Fisher et al. (2015) using an adjusted logistic regression model, found patients had higher odds of having prognostic awareness if they had less than 6 weeks of life versus if they had less than 6 months of life (OR = 2.3; 95% CI=1.8 - 2.9). The sample was comprised of 2090 palliative home care patients in Canada and assessed using the InterRAI Palliative Care (InterRAI PC) Assessment. The InterRAI PC is a qualitative semi structured interview method of communication for ACP designed for adults with EOL needs regardless of care setting. Similarly, Tang and colleague (2019) investigated longitudinal changes in prognostic awareness in the last year of 277 terminal ill patients. Prognostic awareness was measured as the knowledge that one could not be cured and could die soon. Results showed prognostic awareness increased temporally as one approached EOL. Compared to 181-365 days before death, prognostic awareness increased by 1.51 times (95% CI: 1.02 – 2.15) when patients were 91-180 days to death, 2.09 times (95% CI: 1.37 – 3.17) when patients were 31-90 days to death, and 3.21 times (95% CI: 1.98 – 5.18) when patients were 1-30 days to death.

Awareness is closely related and considered to be a key component of preparedness and dying with dignity. Lokker et al. (2012) performed correlation statistics on a sample of 475 nurses and caregivers of deceased patients. Patients were more likely to die with dignity and be prepared when aware of dying. Awareness was correlated with readiness for ACP. Nurses reported an 8% increase in awareness after the introduction of a guided advance care plan that facilitated communication. In the retrospective medical record review, awareness increased by 26% after facilitated EOL communication (p=.000). Lehto & Therrian (2010) analyzed 73 patients newly diagnosed with non-small cell lung cancer. Preparedness was a primary concern identified by 64% of the sample. Completion of EOL plans were positively correlated with awareness of death and better end of life plans. In a qualitative study of 19 Dutch patients, early awareness of prognosis was associated with better preparedness (Francke & Willems; 2005). The extent to which the factor of awareness contributed to preparedness has not been studied in the literature but suggested.

Richards, Ingleton, Gardiner and Gott (2013) investigated awareness among thirteen palliative patients using qualitative thematic analysis. Participants who were unaware of their prognosis were reluctant to engage in EOL communication and displayed no state of preparedness. The theme was entitled “as long as I can cope, I’m not interested”. Interestingly, this study also supported the existence of life limiting illness is a necessary antecedent to preparedness, however patients can avoid preparedness by displaying a reluctance to engage in acquiring knowledge and awareness of their life limiting illness.

Awareness and existential reflection were examined by an interpretative qualitative study (Tong et al., 2016) whose stratified purposive sampling plan recruited 16 participants with cancer by a baseline assessment of the Death and Dying Distress Scale (DADDS). Participants narratives about EOL and communications about distress were stratified by low, moderate, and high DADDS scores. The distinction between awareness, acceptance and fear of death appeared to differ by coping. Participants with low DADDS scores exhibited psychological readiness for thoughts related to EOL, conveyed an awareness of the threat of mortality but were not necessarily demonstrating acceptance. Prior experience with death and resiliency emerged as a theme that allowed individuals to cope with EOL communication and acknowledge acceptance of life limiting illness.

Wen et al. (2022) conducted a longitudinal cohort study sampling 383 cancer patients in their last six months of life in China. Four previously identified death-preparedness states (no-death-preparedness, cognitive-death-preparedness-only, emotional-death-preparedness-only, and sufficient-death-preparedness states) were compared to anxiety symptoms, depressive symptoms, and QOL using multivariate hierarchical linear modeling and logistic regression modeling. They concluded psychological preparedness for death without accurate prognostic accurate awareness may lead to potentially inappropriate life prolonging treatment and lack of hospice care at EOL. Patients in the emotional-death-preparedness-only state were more (OR [95% CI] =2.38 [1.14, 4.97]) and less (OR [95% CI] =0.38 [0.15, 0.94]) likely to receive chemotherapy/immunotherapy and hospice care, respectively. The study acknowledged that poor prognosis awareness without emotional preparedness effected QOL for terminal cancer patients.

Acceptance

Gesser, Wong & Reker (1988) conceptualized death acceptance within their Death Attitude Profile Revised (DAP-R). Gesser et al. (1987) defined death acceptance “as being psychologically prepared for the final exit” p.8. Three definitions of acceptance were postulated: (1) Neutral death acceptance or facing death rationally as an inevitable end of every life; (2) approach acceptance or accepting death as a gateway to a better afterlife, and (3) escape acceptance or choosing death as a better alternative to a painful existence. This definition was validated for twenty-five years by the Death Attitude Profile-Revised (DAP-R) as the preferred instrument for assessing death acceptance (Tomer, Eliason & Wong, 2007; Wong & Tomer, 2011) Klug & Sinha (1987) also defined death acceptance as “the deliberate, intellectual acknowledgement of the prospect of one's own death” and the positive emotional assimilation of the consequences" (p.230). Utilizing these definitions, preparedness requires cognitive awareness and an emotional reaction, but the above research studies operationalized preparedness in terms of the physical outcome of planning for death and not ACP.

Van Camp et al. (2011) concluded that preparedness for ACP and the meaning a patient gives to their life is influenced by the acceptance of death as a possibility, past experiences, and personal fears, one’s internal perceived sense of control of their situation and trust. Utilizing semi structured interviews, Van Camp et al. (2011) supported the idea that non acceptance of life limiting illness made EOL discussions impossible. Therefore, adjustment and acceptance are constructs that are outside of the phenomenon of preparedness. In a qualitative study, Sana (2014) supports the definition of acceptance as a state of choice in response to chronic illness. Acceptance is defined as the state of choice between feeling you can fight the illness or prepare for it (Sana, 2014). According to Sana (2014), preparedness in relationship to acceptance occurs when choice is no longer possible. Therefore, acceptance is an antecedent to preparedness.

In an Australian and American qualitative study, Walczak et al.

(2011) affirmed acceptance as an antecedent to readiness for ACP. Walczak defined acceptance as a precursor to readiness. Acceptance involved acknowledging death while maintaining hope and being able to accept uncertainty in their disease trajectory. Acceptance of EOL may be inevitable and with EOL communication people can become prepared. Fleming and colleagues (2016) suggested that acceptance of EOL is inevitable and sought to understand advanced elderly persons preferences for care at EOL and their attitudes related to EOL. A longitudinal qualitative interview of 42 participants aged 95 to 101 years was conducted. Thematic analysis revealed readiness to die was prevalent, expected and accompanied by recurrent thoughts about dying.

Non acceptance of nearing death is an important variable that hinders preparedness in EOL communication. In an exploratory qualitative survey, elderly patients with a median age of 81 years were recruited from three geriatric settings; a nursing home, home, and a palliative oncology hospital unit (Piers et al., 2011). The purpose of the study was to explore elderly perceptions of ACP and reasons for participation or nonparticipation in the process. The authors suggest that clinicians should focus EOL discussions on three areas: (1) death acceptance, (2) patient preparedness to plan his/her EoL plan and (3) patient’s personal experiences with death including trust in provider and caregiver to make EOL decisions for them. Elderly patients appeared to desire EOL discussions that were related to addressing their personal experiences and fears. However, addressing issues related to limiting LSTs (i.e., ventilators) did not have meaning for them. Therefore, assessing preparedness has implications for focusing EOL discussions on the personal preferences, values, and beliefs of the patient. Patients who completed advance care plans shifted and vacillated between acceptance and nonacceptance of dying. This study had limited applicability to the present study as the view focused on physician's skill and role in creating trust in EOL communication. Limitations of the study included selection bias and presence of individuals with cognitive impairment within the sample.

Mack et al. (2008) developed a measure to assess acceptance at EOL for patients with terminal illness. The *Peace, Equanimity and Acceptance in the Cancer Experience (PEACE)* questionnaire was administered to 160 advanced cancer patients to assess cognitive acceptance of EOL. The 12-item PEACE questionnaire had internal consistency (Cronbach's alpha =.85) and included a 5-item Peaceful Acceptance of Illness subscale (Cronbach's alpha =.78) and a 7-item Struggle with Illness subscale (Cronbach's alpha =.81). Both subscales had inverse associations with each other regarding peace (r=.66, p<.0001 for acceptance; r= -.37, p<.0001 for struggle). Although there was no statistical difference between awareness and acceptance, individuals who were aware of EOL had a statistically higher struggle with illness (14.9 versus 12.4; p= .001). Struggle with illness was higher for patients with ADs even after adjustment for acceptance (means 14.0 versus 11.8; p=.04). Postmortem EOL outcome data was attainable for 56 participants. The PEACE measure has applicability to this proposed study as the cross-sectional data of port mortem participants revealed no associations between acceptance and proximity of EOL (r=.09, p =.48). This suggests PEACE as a potential questionnaire in measuring acceptance for EOL planning. A limitation of PEACE is the scale lacks items for concerns about ACP being a process.

Wentlandt et al. (2012) examined the sociodemographic and clinical factors associated with better preparedness for death. Recruiting a sample of 469 advanced cancer patients, the personal and relational factors associated with better preparation for ACP and EOL were older age, living alone and decreased death anxiety (i.e., fear of death). Krauss et al. (2015) also supported that preparation for ACP was associated with decreased fear of death in advanced cancer patients. The five item Preparation for End-of-Life subscale of the Quality of Life at the End of Life (QUAL-E) scale was utilized in both studies to assess preparedness in a binary fashion. The internal consistency of the preparation for EoL subscale, in a validation study of 248 patients was poor (Cronbach's alpha = .68; Steinhauser et al., 2004). Subsequent studies have also demonstrated low internal consistency (Cronbach's alpha =.64) for preparation at end of life (Grunke et al., 2017). The QUAL-E validation study included patients with advanced chronic illness; stage IV cancer, CHF, COPD and ESRD. Preparation in this subscale was focused on financial and mental reflection on life's regrets and perception of one's loved ones for the individual's death. Although inadequately focused on the internal attributes of preparedness, QUAL-E supports preparation for ACP as a process and its measurement assesses EOL among patients with advanced chronic illness.

Historically, research supports awareness of illness, thinking, willingness and motivations as components of preparation. Contrary to the view of Gesser et al. (1988), this study hypothesizes that acceptance is passive and does not adequately inform preparation (Sun, Y. personal communication, 2013). Acceptance implies agreement with a belief or willingness to tolerate a difficult or unpleasant situation (Merriam-Webster, 2019). Tolerating death or terminal prognosis as in acceptance is vastly different than a state of readiness, awareness, and wiliness to engage in the ACP process as in preparedness. Conceptually, preparedness is multidimensional and may not correlate with truly accepting that one is at EOL. Moreover, health related anxiety and/ or fear of death potentially creates terror that must be mediated and abated prior to an individual being engaged in a willingness to create an advance care plan.

Fear of Death vs. Health-Related Anxiety

Patients fear the consequence of disease progress in chronic illness and ultimately demonstrate a universal fear death. In a multinational mixed method descriptive quantitative analysis with a qualitative component, 442 patients received ACP as an intervention (Zwakman, Delden et al., 2020). In total, 33% of 442 patients who received the intervention completed an AD form. Document completion varied per country: 1.4% (United Kingdom), 2.6% (Denmark), 29.2% (Belgium), 41.7% (the Netherlands), 61.3% (Italy) and 63.9% (Slovenia). Patients from all participating countries feared the consequences of disease progression.

Porritt (2001) performed a qualitative phenomenological study to investigate the phenomenon of preparedness in ten dying participants. Fear of death was expressed as being abated by emotional and psychological attitudes in participants who expressed a readiness to die. Fear of death has been conceptualized in nursing research as a response to awareness of life limiting conditions (Lehto & Stein, 2009; Neimeyer, Moser, & Wittkowski, 2003). Fear of death, death awareness and acceptance have been found to be mediated by cultural beliefs, access to healthcare, functional health literacy and self-esteem (Gesser, Wong & Reker, 1988; Klug & Sinha, 1987; Neimeyer et al., 2003; Neimeyer, Wittowski & Moser, 2004; Wittowski, 2001). The above-mentioned sociodemographic, intrapersonal, and external mediating factors have also been shown to influence preparedness.

Several studies have demonstrated that death awareness and fear of death are confounded by variables that include gender, demographic data, religiosity, social support, and self-esteem (Burke, Martens & Faucher, 2010; Cicirelli, 2002; Florian & Kravitz, 1983; Florian, Mikulincer, & Hirschberger, 2002; Vail et al., 2012). For example, interpersonal relationships and social support mitigates fear of death, while death awareness leads to an attempt to improve physical functioning through health seeking behaviors. Therefore, confounding variables of fear of death include health seeking behaviors as well as social support and cultural beliefs.

Due to the complexity and inverse relationships of anxiety and fear, studies assessing attitudes at have utilized multiple instruments to assess the multidimensional aspects of the psychological contribution to EOL decision making. Neimeyer, Moser & Wittowski (2004) focused on reviewing psychometrics for nine general questionnaires for measuring death anxiety, fear, threat, and acceptance. In addition, they also suggested measures for coping and readiness. Readiness was conceptualized as a positive appraisal while fear and threat were viewed as a negative appraisal. The general scales reviewed were unidimensional and included the Death Anxiety Scale (Templer, 1970), The Revised Death Anxiety Scale (McMordie, 1982), the Collett-Lester Fear of Death Scale (Collett & Lester, 1969), the Threat Index (Krieger, Epting, & Leitner, 1974; Neimeyer 1994), the Multidimensional Fear of Death Scale (Hoelter, 1979), the Death Depression Scale (Templer, Lavoie, Chalgujian, & Thomas-Dobson, 1990) and the Fear of Personal Death Scale (Florian & Kravetz, 1983). Unidimensional modeling, poor internal consistency, and limited correlations with relevant constructs of awareness and acceptance are significant limitations to most of the aforementioned scales. The Fear of Personal Death Scale (Florian & Kravetz, 1983), the and the Multidimensional Orientation toward Dying and Death Inventory (MODDI-F, Wittkowski, 2001) are notable exceptions.

Florian and colleagues comprised a multidimensional theoretical model of fear of personal death that included three dimensions of meanings people attach to their fear of death;

intrapersonal, interpersonal, and transpersonal meanings (Florian & Har-Even, 1983; Florian & Kravetz, 1983; Florian, Kravetz, & Frankel, 1984; Florian & Mikulincher, 1997; 2004; Mikulincher & Florian, 2006). The intrapersonal dimension includes concerns related to the consequences of death for one's own mind and body, such as fear of the failure to accomplish important life goals and to have meaningful personal experiences. The interpersonal dimension includes concerns related to the effects of death on family, friends, and intimate relationships. The transpersonal dimension includes personal concerns related to the afterlife.

Florian and colleagues applied their multidimensional model of fear of death within a Terror Management Theory (TMT) framework to content analysis to create both the Fear of Personal Death Scale (FPDS) and Thematic Appreciation Task. Florian & Mikulincer (1997) hypothesized that the activation of fear of death concerns induced by threats to mortality depends on (a) the intrapersonal, interpersonal, and transpersonal concerns, (b) the specific concerns attached to the death threat itself and (c) the ability of cultural beliefs and worldview to buffer the predominant fear of death. Routledge & Juhl (2010) concluded that death awareness particularly increases fear of death among those who lack personal meaning in life.

The FPDS is comprised of 31 items that the respondent rates on 7-point Likert scales reflecting degree of agreement or disagreement with each item. Factors and representative items assess three domains. Intrapersonal concerns include: 1) Loss of self-fulfillment; and 2) Self-annihilation. Interpersonal concerns include: 3) Loss of social identity; and 4) Consequences to family and friends. Finally: 5) Transcendental consequences (e.g., Death frightens me because of the uncertainty of any sort of existence after death); and 6) Punishment in the afterlife. Internal consistency has demonstrated Cronbach's α ranges from .73 to .90 (Neimeyer et al, 2005). Although uncertainty is a component of the scale, unconscious thoughts are more related to uncertainty in the hereafter than related to diagnosis or prognosis.

The Multidimensional Orientation toward Dying and Death Inventory (MODDI-F, Wittkowski, 2001) like the DAP-R assumes that fear and acceptance coexist as one must consider their own mortality. Internal consistency was demonstrated by Cronbach's alpha range of .82 to .92 (Neimeyer et al., 2005). Wittkowski (2001) demonstrated negative correlations between fear and acceptance in validation studies. The final questionnaire includes eight subscales and 47 Likert items. Subscales include 1) Fear of one's own dying (eight items); 2) Fear of one's own death (six items); 3) Fear of another person's dying (six items); 4) Fear of another person's death (4 items); 5) Fear of corpses (four items); 6) Acceptance of one's own dying and death (eight items); 7) Acceptance of another person's death (six items); and 8) Rejection of one's own death (five items). These subscales address the process of dying and not the process of contemplating dying through ACP. In summary, fear of death is a universal experience and existing scales address the process of dying and not preparedness for ACP.

Advanced care planning as a health behavior occurs in individuals that are not always convinced, they are dying. Health concerns are usually present within most individuals considering ACP. Abramowitz & Braddock (2008) conceptualizes health anxiety in terms of individuals inability to perform appropriate health related actions in response to perceived threats. Health anxiety represents maladaptive coping. Health anxiety is defined as the experience of excessive fears or beliefs concerning a serious illness, potentially due to excessive worry about symptoms and misinterpretation of physical symptoms and sensations (Abarmowitz & Braddock, 2008). Health anxiety is a dimensional construct existing on a continuum with minimal worry about illness at one end and excessive anxiety at the other (Alberts et al., 2013).

Health anxiety has been measured in literature using the Short Health Anxiety Inventory (SHAI; Salkovskis et al., 2002). Prior instruments measuring fear of death or health anxiety included items regarding death and/or physical illness, and the endorsement of such items resulted in elevated scores in individuals who were temporarily sick or diagnosed with chronic illness. The SHAI was designed to reduce this bias, making it appropriate for use with the public. The SHAI is a 14-item measure of health-related worry, awareness of physical changes and sensations, and feared consequences of having an illness over the previous 6 months (e.g., "I spend most of my time worrying about my health"). Participants selected the response option that best reflects their feelings on a Likert scale of 0 to 3 (e.g., "As a rule I am not afraid that I have a serious illness" to "I am always afraid that I have a serious illness"). Total scores are calculated by summing across item responses and greater scores indicate greater health anxiety. The 14-item SHAI has two factor scales: one assessing the tendency to experience health-related thoughts that are unwanted and recurrent (i.e., Thought Intrusion; Troublesome Thoughts) and one pertaining to fears of having – or the idea that one has – a serious medical condition (i.e., Fear of Illness) (Alberts et al., 2013). Internal consistency demonstrated a Cronbach's α =.84 with a test-retest reliability of (r = .87) (Alberts et al., 2013).

Abramowitz, Deacon and Valentiner (2007) examined the psychometric properties of SHAI in a healthy non-clinical sample utilizing a cognitive-behavioral conceptual framework. According to the cognitive-behavioral framework of health anxiety, troublesome catastrophic thoughts activate fear and triggers anxiety and uncertainty. The uncertainty triggers safety seeking strategies to cope with their health-related anxiety, such as avoidance. The 18 item SHAI instrument, the Illness Attitudes Scale (Kellner,1986) and the Intolerance of Uncertainty Scale (Freeston et al., 1994) were administered to 467 undergraduate students. Intolerance of uncertainty was predictive of health anxiety and highly correlated.

Intrapersonal & External Influencers of Preparedness.

Sociodemographic, intrapersonal, and external influences are modifying factors of death attitudes that mediate preparedness for ACP. This conceptual model has been synthesized over the past decade from concept analysis, decision-making models, and clinical experiences in professional practice with patients, families, and health care clinicians participating in collaborative decision- making at EOL. Personal influences on preparedness include sociodemographic data (age, gender, income etc.), health literacy, religiosity, personal beliefs, values, health literacy and prior experiences with EOL. External influences such as presence of hope, decisional conflict, clinician ACP communication experience, the clinician patient relationship, social support, diagnosis, prognostication, symptom burden, temporal nearness of death, and uncertainty have also been reported as affecting preparedness (Feifel, 1969; Hong, Yi, Johnson & Adamek, 2017; Sanders, Robinson & Block, 2016; Sanders et al., 2019; Volandes et al., 2008; Wentlandt et al; 2012). For the purpose of this study, sociodemographic data, and prior experiences with EOL will be examined.

Variations in preparedness and completion of ADs are not well researched or understood (Fried, et al., 2010). Ruff et al. (2011) performed an extensive review of the literature to identify the factors that affect preparation for ACP and EOL decision making. Four topics of EOL care were surveyed: EOL planning, treatment preferences at end of life, comfort with EOL communication and prior knowledge/opinions of hospice. Stepwise linear regression was utilized to determine the association between preparedness for ACP outcomes (e.g., having an AD, knowledge of hospice) and EOL care and communication. The regression model for EoL care demonstrated that older age, absence of religious affiliation and prior knowledge of hospice accounted for 13% of the variance in desiring limited life sustaining interventions at EoL. Higher educational level, existence of an AD and prior knowledge of hospice accounted for 18% of the variance in experiencing preparedness and comfort with EoL discussions.

Purpose of the Research

There is a significant gap in present nursing research related to the assessment of patient preparedness to participate in ACP. Preparedness should be the focus of research to explore areas to improve AD planning and acceptance of palliation of chronic health conditions (McLeod-Sordjan, 2013). The research problem exists that the existing instruments do not capture the complex and dynamic nature of preparedness for ACP. Items are needed to help clinicians identify not only individual patient's level of preparedness, but also patient's thoughts, knowledge, and willingness to engage in EOL conversation. This study will address this gap by developing and validating a comprehensive instrument that measures patient's preparedness for ACP to help assess readiness for EOL communication. Findings from this study will assist in EOL research and progress ACP practice. A reliable and valid scale of preparedness can support future intervention studies testing EOL communication practices and aid future researchers to identify the correlation between EOL communication, utilization of life sustaining technology and patient-centered quality of death.

Significance of the Study

Guidelines and systematic reviews of EOL issues suggest that effective communication of prognosis, exploration of death attitudes toward ADs and appreciation of cultural preferences can improve EOL decision making (Fawole et al. 2012; Piers et al., 2011; Searight & Gafford, 2005). Discussing prognosis and EOL care issues can enable development of an advance care plan that maximizes clinical and quality of life outcomes. However, to initiate the EOL discussion, the clinician should understand how prepared their clients are and what topics to start with before engaging in difficult conversations. The multidimensional nature of preparedness includes psychological attitudes developed after the appraisal of uncertainty and incorporates intrapersonal factors.

Future research studies can use this comprehensive tool to assess patients' preparedness over time, identify factors influencing preparedness and design research interventions to improve patient's preparedness for ACP. Clinicians can use the tool to identify at what level and stage their clients are prepared for ACP and for which components of ACP. This assessment will help clinicians design effective communication strategies that tailor to individual patient's level of preparedness for ACP. Nurses can also use the tool to design guidelines to improve nurse-patient communication. The developed tool can also be incorporated into nursing curriculum and staff development to educate nursing students and practice nurses about patients' preparedness for ACP.

Significance to Nursing

It is significant to nursing to determine the relationship between preparedness and patient related ACP decision making. Existentialism seen in qualitative nurse researchers such as Benner and Parse, underpins the importance of nursing presence for patients and caregivers during EoL. Nurses have the ability to bear witness to the EOL phenomenon and make a significant difference in the patient's dying experience. Assessing patient preparedness for

ACP is the initial nursing intervention to create a patient centered plan. Research has suggested that those who have not prepared for ACP are less likely to have an EoL care plan (i.e., advance directives). Better preparing chronic patients for ACP can improve healthcare utilization and alleviate caregiver burden by decreasing ambiguity regarding patient's wishes and values related to EOL care. Future studies can use the developed instrument to create effective and standardized approaches to ACP discussions, including how to tailor information to patients with different levels of preparedness and how to present prognostic information to patients and caregivers with different areas/aspects of preparedness. In addition, the instrument can be used to train clinicians in assessing, initiating and documenting patient readiness for EoL discussion and ACP.

Chapter Summary

This chapter highlights the different perspectives of preparedness for ACP. Research has suggested that those who have not prepared for death are less likely to have an EOL care plan (i.e., advance directives). In the literature, existing instruments that attempt to measure the construct of readiness do so utilizing theories related to TTM. Theories related to TTM, conceptualizes readiness as a behavior and incompletely capture the cognitive component of preparedness for ACP. The variability of readiness demonstrated by Sudore, Fried and Sakai and colleagues can be attributed to conceptualizing readiness as a process of change. The provision of ACP interventions and EOL communication is unlikely to demonstrate success unless the assessment of psychological readiness occurs. More rigorous studies should be done on ACP process from a patient perspective. Preparedness for ACP may potentially never develop in the trajectory of illness without intervention therefore clinicians need an objective measure to signal readiness for ACP. The conceptual definition of preparedness is a promising area of nursing scientific research for exploration of the patient's psychological attitudes after appraisal of uncertainty. The attributes of preparedness include thinking, knowledge (desire to know), willingness, and existential reflection. Preparedness is iterative and mediated by routine communication and uncertainty.

Chapter III: Methodology

Purpose of the Study

The purpose of this chapter is to describe the methodology used to develop and validate an instrument measuring preparedness for ACP to support patient outcomes, clinical practice, and knowledge development. The developed instrument will help nurses and other clinicians assess patient's preparedness for EoL discussion and ACP. Additionally, the developed instrument can facilitate earlier EoL communication thereby improving patient and caregiver satisfaction with EoL care. In this study, the literature review highlighted in Chapter II led to the selection of the factors and measurements detailed below. All the factors in the conceptual framework will not be examined because the purpose of this study is to validate the developed instrument. Based on the COSMIN study (Mokkink et al., 2019), the psychometrics for the advance planning Preparedness Scale (APPS) to be evaluated are as follows:

1. Content validity through a panel of experts and patients as indicated by Content Validity Indices and qualitative feedback.
2. Internal consistency as indicated by Cronbach's α values
3. Test-retest reliability within a 48–96-hour interval
4. Construct validity through exploratory factor analysis and confirmatory factor analysis.
5. Construct validity through hypothesis testing. The hypotheses to be tested are as follows:
   (a) There is a moderate negative relationship (correlation coefficient $r < -.5$) between APPS scores and the 23-item Mishel Uncertainty in Illness Scale (MUIS-C)

scores.

(b) The APPS scores have strong correlations (correlation coefficient *r* > .7) with the existing advance care planning Readiness Instrument (ACPRI)

(c) The APPS scores will demonstrate moderate correlation (correlation coefficient *r* between .5 and .7) with the Struggle with Illness and the Peaceful Acceptance subscales of the PEACE questionnaire

(d) The APPS scores will demonstrate moderate correlation (correlation coefficient r between - .5 and – .7) with the short health anxiety inventory (SHAI)

6. Criterion validity using the actual outcomes of ACP (such as signed AD, living will, health care proxy, durable health power of attorney, MOLST etc.)

Research questions related to additional performance of the APPS are:

1. To what extent does the APPS correlate with social desirability as measured by the Shortened Marlowe-Crowne Social Desirability Scale (MCSDS)**?**
2. What characteristics of patients are correlated with the preparedness for advance care planning and subscales of the newly developedadvance planning Preparedness Scale (APPS)?
3. To what extent does the components examined in the theoretical model predict preparedness?

Hypotheses to compare the performance of the APPS and ACPRI are:

1. the Advance Planning Preparedness Scale will have better criterion validity than the ACPRI?
2. The correlation of social desirability with APPS is significantly lower than that with ACPRI.

Process for Instrument Development

This study consists of three phases and 9 steps guided by the best practice for developing and validating scales (Polit & Beck, 2020; Polit & Young, 2016). Phase I is item development which includes 3 steps, conceptualization of constructs, generation of an item pool for each domain/construct, and development of instructions, item responses and scoring methods. Phase II is the preliminary evaluation of the items, which include self-evaluation of readability and content validity assessed by panels of content experts and target population (steps 4 and 5). The initial item pool will be revised based on readability test and the content validity results, and pilot tested in a small sample of target population (step 6). The revised instrument will be used in Phase III, field testing, in which psychometric properties will be evaluated. Phase III include 3 steps, developing sampling and data collection plans (step 7), administrating the instruments, and collecting data (step 8), and analyzing data to determine internal consistency, construct validity, criterion validity and test-retest reliability (step 9). The following sections describe the steps that will be taken in developing and validating the APP.

Phase I: Item Development

Step 1. Conceptualizing the construct

The first step in instrument development is to thoroughly analyze and ascertain the definition of the concept and its underlying construct to be measured. The conceptual definition and attributes of preparedness for ACP are based on a thorough review of literature, clinical observations of patients, and theories. The conceptual definition of preparedness as utilized in this study can be found in Chapter II, the review of the literature section on page 4. There are 5 main attributes that can be associated to preparedness: psychological comfort with advance care planning, knowledge (desire to know) about ACP, troublesome thoughts about ACP, willingness related to ACP, and existential reflection related to ACP.

Step 2. Developing an item pool

Items in an instrument collectively contribute to the operational definition of the concept to be measured. According to Polit and Yang (2016), the item pool should have 50% more items than the final instrument. Devellis (2012) recommends starting with three to four times items as the final scale. About 55 items (Appendix A) have been generated from the literature review and existing instruments.

Wording. Items were worded devoid of potentially biased terms of social identity, i.e., gender, religion, ethnicity, race, economic status, or sexual orientation. The development of the scales took into consideration clarity by utilizing the Health and Human Services (HHS) national standards for Culturally and Linguistically Appropriate Services (CLAS) with an educational and reading level of the sixth to seventh grade. Negative stems, double negative and double-barreled items were avoided to prevent confusion (Polit & Yang, 2016). In addition, items were worded to avoid use of medical jargon, colloquialism and prevent question bias.

Step 3. Developing response options and scoring methods

Item responses. Rating scales are most commonly used within nursing research. Polytomous response options will be utilized to yield better discriminatory information regarding the construct of preparedness. A five-point Likert Scale will be used to assess the response to each item from (1) *Strongly Agree to (5) Strongly Disagree.*

Scoring. The next step in instrument development is to decide how to express the final score in a meaningful way. There are two commonly used methods to calculate the final score of an instrument. One is to simply add or average the responses on individual items (CTT). The other way is to give weights to each item or subscale if the contribution of each item or subscale to the total score is different (IRT). Multiple regression and results from exploratory factor analysis will be used to determine the weights of items and subscales. In this study, CTT will be utilized to initially explore scoring of preparedness.

Phase II: Preliminary evaluation of the items

Step 4. Internal Review of Readability

Due to the likelihood that APPS will be utilized within hospitalized and ambulatory settings in patients with advanced chronic illness, it was necessary to assess readability. Therefore, the APP questionnaire was tested for Flesch-Kincaid grade level and the Flesch Reading Ease Score through the Microsoft Word program. Reading ease scores rate text on a 100-point scale, with higher values indicating greater ease. Reading ease scores that are considered acceptable for the general population should be in the range of 65-70, and the scale's readability to be on a sixth or seventh grade level or lower (Polit & Yang, 2016).

Deciding item features.

A set of items that represented the key characteristics of each attribute (subscale) in slightly different ways was developed to cancel out the irrelevant idiosyncrasies of individual items. This was supported by Cronbach's alpha values, which is discussed in Chapter 4. A total of 55 items were developed and proposed for the APP questionnaire with five subscales.

Step 5. Expert review for Content Validity

A panel of 23 professional and patient experts assessed content validity of the items. The aim of the expert panel review was to revise or eliminate ambiguous, irrelevant, and inappropriate items from the instrument. Purposeful, networking and snowball sampling methods was used to recruit potentially eligible expert reviewers. One inclusion criterion for the expert panel was healthcare professionals and patients who are knowledgeable about ACP. These included patients with chronic illness, doctoral prepared nurse practitioners, doctoral prepared social work bioethicist, physician, and nurse members of ethics and/or palliative committees with expertise in bioethics, palliative care, ACP, geriatrics, advanced chronic illness and facilitated communication. The other inclusion criteria were age 18 years or older and able to read English.

Potential eligible participants received an invitation flier and a link for the online content validity survey via email utilizing the Qualtrics survey. The first page of the online survey was three questions to screen for eligibility and the second page the informed consent, which included the purpose of the survey, participant's role in the survey, the time to complete the survey, risks and benefits, voluntary participation, confidentiality, and protection of privacy. Clicking the survey link constituted consent to participate.

Eligible and consented expert panel reviewers were given the theoretical definition of preparedness for ACP. They were also given further explanation to distinguish between preparedness for ACP and other similar concepts such as the readiness for behavioral change and death preparedness. In addition, the reviewers were given identified attributes of the subscales of preparedness and the structure (subscales) of the instrument. (Mokkink et al., 2019; Polit & Yang, 2016; DeVellis, 2012).

The Content Validity Form, a 4-point rating scale (See Appendix B) was completed by the expert review panel via the Qualtrics survey. Reviewers were instructed to determine each item for relevance to the construct. Comprehensiveness was rated by the degree of content coverage of the items and the domains, namely whether all aspects of the concept are covered by the items and the domains. Participants were asked to supply additional information on content areas that were not captured by the instrument as well as suggestions to revise the wording of inappropriate items. Qualitative data related to comprehensibility was further collected in the pilot study using a survey.

Item content validity index (I-CVI) and scale content validity index (S-CVI) was calculated using Microsoft Excel for relevancy, comprehensibility, and comprehensiveness. I-CVI was the proportion in agreement among the expert for each item, computed by the following formula: I-CVI = (the number of experts giving a rating of 3 or 4)/ (total number of experts). Items with CVI -I .8 or greater were kept in the scale without revision while those I-CVI below .8 were revised or discarded based on the expert panel's suggestion. S-CVI was computed by averaging the sum of I-CVIs. A S-CVI value of .9 was utilized as the standard of excellent content validity (Polit & Beck, 2016). The revised instrument was reevaluated by content experts until the above criteria for I-CVI and S-CVI are met.

Protection of Human Subjects. Content experts were recruited through purposive sampling and snowballing techniques. Interested participants were able to click the survey link to screen for eligibility or contact the researcher through email, telephone, or in-person. To minimize potential coercion, the researcher sent content experts the link via email. No financial incentive or coercion was utilized. Eligible participants were informed that their participation is voluntary, and that they could withdraw from the study at any time without giving a reason. A random code was assigned automatically by Qualtrics to each participant and personal, identifiable information was not collected. The coding key was saved in a password protected file and kept separately from the remaining data. The Qualtrics servers are protected by high end firewall system and are regularly scanned to identify and patch any vulnerabilities. Transport Layer Security (TLS) encryption (also known as HTTPS) is used for all transmitted data and survey may be protected with passwords. Participants' responses to the Qualtrics survey were downloaded and saved in password protected computers. Only the research team had access to the collected data.

Step 6. Pilot-testing Questions

After expert content validation, preliminary pilot testing was performed to examine the feasibility of the instrument using both quantitative and qualitative methods. The qualitative survey also evaluated comprehensibility and clarity of the items and instructions.

Purpose. The primary purpose the pilot study was to examine the feasibility of the study as well as qualitative feedback for content validity. Feasibility was assessed by participants in terms of health literacy plain language standards and the time constraints imposed by the sensitive nature of the subject both as a written and internet survey. This included the number of questions to be shown on each page, the order of item, arrangement, potential causes for missing responses, and clarity of instructions and APPS items or any other survey concerns identified by the participants.

Design. The pilot study utilized a mixed method design. The cross-sectional quantitative data was collected using an electronic survey. Participants were obtained from community settings and social media utilizing a link or QR code. In addition to the questionnaires, quantitative data collected via Qualtrics included the average time to complete the questionnaires, missing responses, and the number of questions to be shown on each screen, etc. Qualitative data was collected though open-ended questions which include the order of item, arrangement, potential causes for missing responses, and clarity and difficulty of instructions or any other survey concerns identified by the participants (see Appendix J).

Sampling. A convenient sample of 88 participants with chronic illness was obtained from healthcare facilities and community facilities (e.g., library, community centers, churches etc.). Flyers were distributed via the internet, social media sites, churches, libraries, and local organizations. To be able to participate, respondents were18 years of age or older with the ability to speak and read English and have been diagnosed with a chronic illness. Their mental status was screened by numeracy of a simple addition of the numbers “2” and “3”. The inclusion criteria for these participants will be the same as those in the full- scale study used to test the reliability and validity of the instrument (see Step 7).

Instruments. The instruments in the pilot study included a demographic sheet (see Appendix C), the developedadvance planning Preparedness Scale (APPS), advance care planning Readiness Instrument (ACPRI, Appendix D), the Mishel Uncertainty in Illness Scale (MUIS-C, Appendix E), the PEACE Questionnaire (Appendix F), the short health anxiety inventory (SHAI, Appendix G), and the Socially Desirable Response Set 5-Item Survey (SDRS-5, Appendix H). Details for these questionnaires can be found in in Phase III, “Step 8. Instruments and Data Collection” section on page

Data Collection. Data collection methods include both quantitative survey through Qualtrics and qualitative survey data. Quantitative data was collected through a Qualtrics survey. Respondents were able to access the survey via mobile, tablet or computer. The first page of the Qualtrics survey screened for eligibility and explain the purpose of the pilot testing to persons who are interested in the study. The next page included informed consent information (Appendix I) and clicking the continue button constituted consent. A random code was electronically assigned to each eligible participant and the online survey will be available to those that opt in.

Additional qualitative data was obtained from a thematic analysis of survey questions appended to the quantitative survey. Participants will be asked to evaluate the APPS instructions, items, and response options regarding their comprehensibility. They also examined the number of questions to be shown on each page, the order of each item, arrangement, potential causes for missing responses, clarity of instructions and wording of the questions, and any other survey concerns identified by the participants. Sample qualitative questions can be found in Appendix J.

Data analysis. Data collected through Qualtrics was downloaded and converted into SPSS 29 for data analysis. Descriptive statistics, including frequency distributions, central tendency (mean, median), and variability (range and Standard Deviation) were calculated to describe demographic characteristics and other study variables. Response rate, responding time and time to complete the entire survey was analyzed by frequency distributions, central tendency (mean, median), and variability (range and Standard Deviation). The average and the total scores for the entire scale and each subscale was calculated using CTT. Feedback elicited through the open-ended questions utilized an impressionistic content analysis. The APPS was revised, and the order of the instruments in the package was based on the results of the data analysis.

Protection of human subjects. The pilot test was designed to ensure sound ethical principles and protect human rights. Interested, eligible participate accessed a copy of the informed consent form, which was available in electronic format when they clicked the survey link. A hard copy of the written consent was available for printout upon participant request. For the quantitative data collected using Qualtrics, the protection of human subjects is like that in Step 5 on p. 94 and the full-scale study in the section labeled “Ethical considerations” on page 108. Participants were able to leave the survey voluntarily and submitting the data will constitute consent for participation for the qualitative data. Participants were informed that the collected data will be kept confidential and asked not to share the information discussed on the survey. However, there is no guarantee that some participants may breach confidentiality.

Phase III: Full-Scale Study and Validation

The purpose of the full-scale study was to examine internal consistency, test-retest reliability, construct validity and criterion-related validity of the APPS which was developed and revised in Phases I and II. The definitions for these measurement properties and the methods to test the psychometrics are guided by the COnsensus-based Standards for the selection of health Measurement Instrument (COSMIN, Mokkink et al. 2019). Detailed research questions and hypotheses can be found on pp. 89-90, the very beginning of this chapter. The following sections will describe sampling, instruments, data collection, protection of human subjects, and data analysis.

Step 7. Sampling Plan

Participants. The inclusion criteria for this study are as follows:

(1) Participants must be 18 years of age and older, male, or female.
(2) All participants must be able to read English.
(3) Participants must have a self-reported diagnosis that demonstrates a chronic illness (e.g., chronic obstructive pulmonary disease, stroke, cancer etc.).

Only individuals deemed to have capacity to make independent decision and be able to complete the study tasks were invited to participate. Access of the survey required literacy and numeracy to access.

Sampling method and sample size. Participants in the full study met the same inclusion and exclusion criteria as the pilot study. The full-scale sampling method were obtained by convenience. Participants were proportionally recruited from multiple sites to enhance the representativeness of the sample with various levels of preparedness. The make-up of the full study sample was from multiple community and general population settings. Additional efforts were made to include individuals from diverse backgrounds by reaching out to churches, community settings and internet recruitment. There is no consensus regarding the sample size for testing an instrument. According to Polit and Beck (2020), recommendations range from three or four respondents per item, with 10 per item being the most used number. Estimation of Sample size for the full-scale study is based on the number of participants needed for Confirmatory Factor Analysis using Soper's A-priori Sample Size Calculator for Structural Equation Modeling (Soper, 2022). Considering 30-35 items in the APPS, 5 subscales and an effect size of .1, plus 15% of missing responses, the estimated sample size was 400 to achieve a power of .8 at .05 significance level. For the test-retest reliability, sample size is calculated using Arifin's web-based sample size calculators for Intra Class Coefficient (Arifin, 2022). With the minimum expected comparative fit index (CFI) of .9, acceptable reliability set at .7 and expected reliability .8, 180 participants were needed to achieve a power of .8 at .05 significant level, with a 15% drop-out rate.

Recruiting participants. Potential eligible participants were recruited from the general public in the United States, including academic and community settings. Multiple recruitment methods such as flyer distribution and/or in person was used. Flyers were placed and distributed in community and church facilities in lobby, dining, and common areas. Screening questions for eligibility will include age over 18, ability to read in English and presence of a chronic illness, (e.g., chronic obstructive pulmonary disease, stroke, cancer etc.).

Eligible participants received the link to the online survey via Qualtrics. Qualtrics surveys were also deployed utilizing Amazon Mechanical Turk (MTurk). Additional websites utilizing Reddit, Facebook and Classified also distributed the flyer. A unique survey number was assigned to each participant and personal, identifiable information was not collected within the Qualtrics survey. A link to a separate survey was used to collect participants' contact information for the re-test. Initially, participants were emailed the retest link. Due to lower response rates; Qualtrics survey was updated with a display logic that revealed the retest link to those who agreed to a retest. The coding key was saved in a password protected file and kept separately from the remaining data. Each unique survey number assigned allowed a follow up survey to directly go to the same participant. The researcher actively monitored the response rate and missing data to ensure the minimal sample size was being obtained and that the sample represented a diversity of age.

Step 8. Instrumentation & Data Collection

Two sets of instruments were assembled for online data collections, one for the first test and another for re-test. All instruments were included in the first test. The re-test used only some relevant sociodemographic information and the revised APPS. These instruments include a demographic sheet (Appendix C), the developed Advance Planning Preparedness Scale (APPS), advance care planning Readiness Instrument (ACPRI, Appendix D), the Mishel Uncertainty in Illness Scale (MUIS-C, Appendix E), the Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE, Appendix F), the short health anxiety inventory (SHAI, Appendix G), and the Socially Desirable Response Set 5-Item Survey (SDRS-5, Appendix H).

Demographic Items. A Demographic sheet was used to collect sample characteristics and demographic factors that have been associated with readiness for advanced directive communication and preparedness. The demographic information includes age, ethnicity, religiosity, education, gender, previous exposure to hospice and previous exposure to AD discussions (Alano et al., 2010; Campbell et al., 2007; Mack et al., 2010; Ruff et al., 2011; Skulason et al., 2014). Participants were asked about their advance care plans as indicated by the completion of a MOLST form, DNR, a living will, or a health care proxy form.

Advance Care Planning Readiness Instrument (ACPRI). Calvin & Erikson (2005) developed the Advance Care Planning Readiness Instrument (ACPRI) to assess attitudes of renal patients toward personal preservation and their readiness to discuss an AD. The goal of the ACPRI is also to aid clinicians in determining an individual patient's readiness (i.e., preparedness) for advance planning communication (Calvin et al., 2005). The 30-item instrument with a rating scale of 1-5 with a maximum total score of 150 has a content validity index of .90 and internal consistency (Cronbach α =.73). The instrument, although designed for and piloted with renal patients, contains items applicable to preparedness for advance care planning in any population. In this study, the internal consistency was higher than the initial validity study. The reliability of the ACPRI had a Cronbach's α of .836 with a mean scale of 144.87 (SD 15.72). Item means were 4.83 (Range 2.40-5.6) with inter-item correlations .138.

PEACE Questionnaire. This 12-item measure is composed of two subscales: a 7-item Struggle with Illness (Cronbach's α =.81) and a 5-item Peaceful Acceptance (Cronbach's α = .78) subscale (Mack et al., 2010). Both subscales were associated with patients' self-reported peacefulness (r=.66 for acceptance, P<.0001; r= −0 .37 for struggle, P<.0001.) All items are measured using a 4-point frequency scale (1 = not at all, 4 = to a large extent). Higher scores indicate, respectively, increased struggle with illness or peaceful acceptance. The Struggle with Illness subscale has a significant positive association with ACP activities such as living will formation or healthcare proxy designation. Struggle with Illness scores were associated with cognitive acknowledgement of terminal illness (mean scores 14.9 versus 12.4, p=.001) and some aspects of ACP (living will or health care proxy, mean scores 13.9 versus 11.5, p=.02).

In this study PEACE psychometrics performed similarly to Mack et al. 2008. The reliability of total PEACE 12 item scale had a Cronbach's α of .828 with a mean scale of 35.91 (SD 5.518). Item means were 2.993 (Range 2.932-3.160) with inter-item correlations .287. The subscale of Peaceful Acceptance had a Cronbach's α of .713 with a mean scale of 15.20 (SD 2.558). The 7-item subscale of Struggle with Illness had a Cronbach's α of .802 with a mean scale of 2.71 (SD 3.805).

Mishel Uncertainty in Illness Scale (MUIS). The Mishel Uncertainty in Illness Scale (MUIS) is a self-reported instrument that quantifies the individual's perception of uncertainty in chronic illness. This study utilized the modified twenty-three item version of the Mishel Uncertainty in Illness Scale (MUIS-C; Mishel,1999). Each item is scored from 1 (strongly disagree) to 5 (strongly agree); total scores range from 23 to 65 with higher scores indicating greater uncertainty. The MUIS-C has a Cronbach's α of .87 and includes four subscales, each representing a distinct dimension of uncertainty (ambiguity, complexity, inconsistency, and unpredictability.

This study is most interested in Mishel (1999) revised concept of uncertainty related to probabilistic thinking. In this study the internal consistency of MUIS-C performed below the Cronbach's α of .87 reported by Mishel (1999). The reliability of the MUIS-C had a Cronbach's α of .83 with a mean scale of 73.25 (SD 12.443). Item means were 3.185 (Range 2.438-3.481) with inter-item correlations .167.

Short Health Anxiety Inventory (SHAI). Health anxiety was measured using the SHAI (Salkovskis et al., 2002), a 14-item measure of health-related worry, awareness of physical changes, and feared psychological consequences of having an illness. Response options reflect participants psychological feelings on a rating scale of 0 to 3 (e.g., "As a rule I am not afraid that I have a serious illness" to "I am always afraid that I have a serious illness"). Total scores will be calculated through summation of item responses with higher scores indicating greater health anxiety. Internal consistency for the entire scale was found to have a Cronbach's α = 0.88 (Dattilo et al., 2021). In this study, the reliability of the SHAI had a Cronbach's α of 0.86 with a mean scale of 83.80 (SD 18.81). Item means were 4.66 (Range 4.30-5.59) with iter-item correlations .254.

Socially Desirable Response Set 5-item Survey (SDRS-5). The study used the shortened form to assess an individual's endorsement of socially desirable characteristics (Hays, 1989), which can be completed under one minute. The 5-items use 5-point Likert-type metric ranging from 1 (*definitely true*) to 5 (*definitely false*). The psychometric property of this very short form demonstrates internal consistencies from .66 to .68 across two samples, composite reliability of .70 and acceptable test–retest reliability r = .75. Leite & Bertvas (2005) report MCSDS as a single latent construct.

As aforementioned this scale was utilized to ascertain the social response bias in the sample. In this study, the reliability of the SDRS-5 had a Cronbach's α of .712 with a mean scale of 11.38 (SD 3.33). Item means were 2.28 (Range 2.04-2.36) with inter-item correlations .33 As a single latent construct SDRS-5 performed in a fashion consistent with its composite reliability of .7. As a formative scale with items that are interdependent on each other, internal consistency is not implied (Freeze & Raschke, 2007).

Data Collection Procedures. Data was collected through Qualtrics survey made accessible through Twitter, Facebook, Amazon M Turk, Locanto, Reddit and community settings. The first page of the survey is informed consent (Appendix I) and click the continue button constitutes consent. The 48-to-96-hour interval was chosen for re-test to avoid significant events or conversations that may change the participants preparedness for ACP. The researcher monitored the full test and deployed retest surveys to participants who agreed.

Step 9: Data Analysis

Data collected through Qualtrics was downloaded and converted into SPSS 29 for data analysis. The deidentified data was screened and cleaned to prepare for data analysis. For the developed APPS, both the total scores for the entire scale and each subscale were calculated using CTT. Patterns of missing data were analyzed using SPSS's Missing Value Analysis module. If missing data were not at random, the Multiple Imputation procedure was used to replace missing values (Meyers et al., 2021). For all continuous data, normality was examined by skewness, kurtosis, histogram, Q-Q plot, and Kolmogorov-Smirnov test of normality. Box plot and Stem-leaf plot was used to identify univariate outliers. Descriptive statistics, including frequency distributions, central tendency (mean, median), and variability (range and standard deviation) was calculated to describe demographic characteristics and other study variables.

To examine construct validity through hypotheses testing (hypotheses a to e), bivariate correlational analysis was performed. Data that was normally distributed and the two variables have linear relationship, Pearson correlation was utilized. Curve estimation was used to identify linear and non-linear relationships. Where data was not normally distributed, Spearman Rho correlation was used.

Structural validity was tested using both Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). When conducting EFA, Kaiser-Meyer-Olkin (KMO) and Bartlett's test examined sample adequacy. Scree plot, eigenvalue and percent of variance explained by the factors was used to determine the number of factors. Different factor extraction methods (such as Principal Component Analysis and Principle Axis Factoring) and rotation methods (such as ProMax and varimax rotation) was attempted to find the best factor solution. Communalities, factor loadings, and the correlation matrix were examined to determine item deletion. The second order CFA was conducted based on the EFA results using SPSS AMOS 29. The process to conduct CFA included five steps (a) model specification, (b) model identification, (c) model estimation, (d) model evaluation, and (e) model re-specification. To correct for the data not being normally distributed, maximum likelihood estimates with bootstrapping was performed. Model fit indexes, such as R^2 statistics to *df* ratio, root mean square error of approximation (RMSEA), goodness-of-fit index (GFI), comparative fit index (CFI), normed-fit index (NFI), adjusted goodness-of-fit index (AGFI) and/or parsimonious normed fit index (PNFI) was used to evaluate the identified model. As these model fit index values initially indicated a poor identified model, modification of the initial model was based on the model estimates. The re-specified models were evaluated and compared to the initial model based on Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC) and Browne-Cudeck Criterion (BCC) values (Meyers et al., 2021).

For criterion validity, it is hypothesized that the APPS scores can significantly predict ACP outcomes, such as the completion of an advance directive, living will, health care proxy, durable health power of attorney, or MOLST. Logistic regression was used to test this hypothesis and social desirability was controlled in the logistic regression model. Multi-collinearity problems were assessed across the independent variable prior to conducting factor analysis. Assumptions for multiple regression included: no outliers, linear relationship, multivariate normality, multivariate homogeneity of variance, independence of errors, and absence of collinearity. Distance between outliers was assessed using Mahalanobis distance to check outliers. Generalized linear modelling was utilized as regression technique when outliers were ascertained.

Correlational testing and reliability analysis was utilized to identify the predictors of preparedness. Scatterplots were examined to review to analyze whether there is a linear or curvilinear relationship between APPS and related variables. Assuming a linear relationship, multiple linear regression analyses was conducted to explore factors associated with preparedness to test research question #3. Multiple regression assumes that the residuals are normally distributed and that the independent variables are not highly correlated with each other. Next, all hypothesized independent variables were entered into the model simultaneously (forced entry method). This full model will be followed by a stepwise backward elimination to find out whether each variable remained significant after non-significant covariates were excluded. The absence of multicollinearity were tested using variance inflation factor (VIF) values.

Internal consistency Cronbach's alpha was analyzed for each instrument and their subscales. The preferred Cronbach's alpha for the subscale will be >.8. Test-retest reliability was examined three ways: effect size (mean change score/SD baseline) (Mokkink, et al., 2010), bivariate correlations, and intraclass correlation (ICC) (Polit & Beck, 2016). Minimal important change or reliability coefficients above .80 are preferred.

Correlational analysis was utilized for hypotheses # 2 testing and for research question 2. As aforementioned, when data are normally distributed and the two variables have linear relationship, Pearson correlation will be used. The correlation coefficients among APPS, ACPRI, and MCSDS and their subscales was reported. Asymptotic z-test (Lee & Preacher, 2013) based on Steiger's (1980) Equations was utilized to compare the correlation coefficients of APPS, ACPRI, MIUS_C and MCSDS and their subscales for hypothesis #1 and hypothesis #2 testing.

Ethical Considerations.

The research was designed to ensure sound ethical principles and protect human rights. Institutional Review Board (IRB) review forms was submitted to the IRB of Adelphi University for approval before participant recruitment and data collection. Study flyers (Appendix K) with contact information was posted and distributed at local libraries, national churches, and community centers. The recruitment plan was designed to fully encompass racial, ethnic and gender diversity and exclude prisoners and children. Interested participants were able to click the survey link to screen for eligibility or contact the researcher through email, telephone, or in-person. Interested participants were screened for eligibility by Qualtrics questions. To decrease potential physical burden, participants who did not have the physical reserve to complete a 30–40-minute questionnaire, such as those with a burden of suffering, inadequate pain control, and/or respiratory compromise, were self-excluded from this study.

All interested, eligible participants were informed of the purpose of the study, their role and time to complete the study, the benefit and potential risks associated with the participation. In support of the principle of autonomy, the participants were informed regarding their voluntary participation and withdrawal from the study at any time without negative outcomes.

Multiple strategies were employed to ensure confidentiality and protect the privacy of the participants. The questionnaires were coded, and identifiable, personal information did not appear on the questionnaire. Participants' contact information (email), and the assigned codes was saved in a password protected file separated from the questionnaire data and only the researcher had access to the file. The tool for conducting the survey, Qualtrics is a secure web application that has proper security practice instituted on both network and server(s) that hosts Qualtrics, as well as within the software itself. In particular, the web server and the database server are separate from each other, and both are behind a firewall or in the DMZ The web server has SSL certificates that ensure secure communication with the end users. The collected data was de-identified and exported to SPSS. The SPSS file(s) and the computer used to analyze the data are both password-secured. To protect the population from harm, all participants were informed that they could skip any question on the instruments that they do not wish to answer. In case of any psychological reaction, due to the sensitive nature of the topic, referral was provided to mental health services. To date no participant contacted the researcher or her advisor regarding any distress related to completing the survey.

Chapter Summary

This chapter presented the process of instrument development, including study design, participants and sample size, instruments, data collection and analysis for each phase. In addition, recruitment, consent process, and protection of human subjects were described.

Chapter IV

The purpose of this chapter is to discuss the statistical analysis that was conducted to develop and validate the instrument measuring advance planning preparedness (APPS) by community individuals with chronic advanced illness. The APPS instrument is grounded by the conceptual framework describing the relationship between preparedness, other factors influencing preparedness (e.g., uncertainty, awareness, acceptance, health anxiety) and the outcomes of ACP.

The specific aims of the study are to examine the content validity, internal consistency, and re-test the developed APPS and evaluate construct validity. The study hypothesis testing is to identify if there are significant relationships between preparedness for ACP and patient' uncertainty measured by the Mishel Uncertainty in Illness Scale (MUIS-C), patient' readiness measured by the Advance Care planning Readiness Instrument (ACPRI), patient' struggle with illness and peaceful acceptance measured by the PEACE questionnaire. Additional hypotheses include identifying the significant relationship between preparedness for advance care planning and patient' anxiety measured by the short health anxiety inventory (SHAI).

There are 6 hypotheses, and 3 research questions examined in this study. The APPS total score and a scale score were analyzed to determine ease of scoring via CTT to predict preparedness for ACP. Research question # 1 examines the correlation between APPS cand social desirability. Research question #2 compares MIUS-C, SHAI, ACPRI and PEACE to APPS total score. Research question #3 compares the characteristics of patients prepared for ACP to the developed APPS and its 5 subscales. The developed APPS in this study will predict better completion of preparedness, as indicated by a stronger inverse relationship with uncertainty and anxiety and a direct relationship with peaceful acceptance of illness and readiness.

Preliminary evaluation of the items

The questionnaire scored an overall Flesch-Kincaid reading grade level of 5.9, and a reading ease score of 77.3. The overall Flesch-Kincaid reading grade level and reading ease score of the APP met the suggested criteria as cited by Polit and Yang (2016) for the general population. However, when scoring each question, it was identified that the reading scale range was 2.5 through 9.5. One question scored significantly higher than the 7th reading grade level. Notably, the item was "I prefer to discuss advance care planning when I first get diagnosed with a serious illness" in the psychological comfort with ACP and scored 9.5. The overall reading ease was supported for the total scale, however with content validity, items were revised and omitted to improve the Flesch-Kincaid Reading Level as the tool is designed for the general population. As shown in Table 1, the initial Flesch Kincaid reading level and ease of APPS was geared to a literacy level for 8th grade education level.

Table 1

Initial APPS Reading Score

#	Item	Flesch-Kincaid Reading Level	Flesch-Kincaid Reading Ease
	Psychological comfort with advance care planning		
1	I would feel uneasy if someone talked to me about end-of-life planning	7	56.4
2	I feel at ease when thinking about health care topics related to end-of-life.	5.9	78.8
3	I find it easy to talk about end-of-life related health care.	4.8	83
4	I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.	6.1	85.1

5	I feel ready to discuss who should make health care decisions for me if I am unable to.	7.1	75.7
6	I feel okay when talking about planning for health care related to end of life.	6.8	73.2
7	I am ready to make decisions about end-of-life health care ahead of time	6.4	74.2
8	I would feel uneasy to talk about an end-stage disease with my health care team	5.6	81.6
9	I prefer to make an advance directive when I am healthy	6.4	68.8
10	I feel at ease when saying my feelings about getting sicker	4.9	75.5
11	I feel comfortable talking about how long I have to live.	6.4	68.8
12	I feel ease with being asked about the things that are important to me	5.2	82.6
13	I am comfortable with discussing my wishes at the end of life	6.7	67.7
14	I am open to discuss my emotions about a decline in my health	5.8	72.6
15	I feel comfortable with discussing my health care choices at the end of life	6.8	67.8
Desire to know			
16	I prefer to discuss advance care planning when I first get diagnosed with a serious illness.	9.5	55.2
17	I desire to know more about advance care planning	7.2	61.3
18	I need to know about advance directives	6	64.4
19	I want to know the choices about treatments at the end of my life	4.4	9.1
20	I want to know the nature of the medical problems I have	4.8	78.2
21	I desire facts about my health to help me make my own end of life decisions	6	80
22	I prefer to discuss the pros and cons of CPR at end of life	4.8	83.7
23	I want to know if I have an illness that is life threatening	3.6	92.1
24	I do not want to know about a condition that will cause my imminent death	6.4	74.2
25	I want to know about options to limit intensive care at end of life	6.4	51.9
26	I need knowledge about illnesses that are life threatening	6.8	62.3
27	I do not want to have knowledge about a condition that will cause my death	5.6	81.6
28	I prefer to have the true facts about whether my illness is terminal	7.2	66.7
29	I want to know what an advanced directive is	3.7	81.3
30	I want to know the odds that I may lose ability to make my own health care choices.	5.6	87
Thinking			
31	I don't want to think about an end-of-life talk with my provider	5.6	76.2
32	I have weighed quantity versus quality of life	6.4	63.4
33	I have thought about the pros and cons of having an advanced directive	6	75.2
34	I have thought about my illnesses getting worse.	6.8	62.3
35	I have thought about what I would want when I get really sick	3.6	92.1
36	I have thoughts that my illness will not get better	2.5	92.1

37	I have thought about having an advance directive	7.2	55.9
38	I think about the things I still want to do in this life.	2.5	100
39	I think about my preferences for end-of-life care	4.8	78.2
40	I have thoughts about people I value	3.7	81.3
41	I think about my values I want to maintain at the end of life	4	91.1
Willingness			
42	I am not willing to engage in advance care planning	4.8	78.2
43	I am willing to say my wishes ahead of time about limits to care at end of life	6.8	78.6
44	If asked to, I will discuss my end of life wishes with my health care team	4.8	89.1
45	I am not willing to talk about health care issues related to end of life	5.6	81.6
46	I am willing to talk about my illness with family that are dear to me	5.6	81
47	I am willing to talk about my end of life with my doctors and nurses	4.4	9.1
Existential Reflection			
48	I have an illness that is life threatening	4.1	8.3
49	I do not have a condition that will cause my death	2.9	94.2
50	I want to focus on the meaning of life when I approach the end of life	5.2	88.1
51	I have imagined a scenario where my illness will cause my life to end	6.4	74.2
52	I am peaceful when reflecting about the end of my life	5.2	77.2
53	I am satisfied with the meaning I have given to my life	4.4	84.7

Content Validity by Expert Panel

Characteristics of the Expert Panel

A total of 21 of 22 participants completed the expert panel review survey. The expert panel was composed of 81% female (n=17) and 19% male (n=4) participants. The average age of the participants was 57.81years (SD =15.06, ranging from 30 to 81 years of old). The expert panel was 78.26% White (n=18), 8.7% Black (n=2), 4.35% Asian (n=1), 4.35% American Indian or Alaska Native (n=1) and 4.35% Other-Latino (n=1). Of the sample, 2 participants identified as Hispanic. The sample consisted of 10 nurses, 7 physicians, 2 clinical ethicists and 4 patients. Sixty percent of the sample had a chronic illness which included cancer, diabetes, hypertension, asthma, hypothyroidism, and mild dementia. Eighty percent of the sample had a health care proxy and 52.63% of the sample had a living will. However, 63.6% of the sample had not left written directions regarding end-of-life care.

Content validity

The expert panel rated each of the APP'S questions for relevancy, comprehensibility, and comprehensiveness. For each question, I-CVI and S-CVI were computed. Experts rated comprehensiveness and comprehensibility at a 3or 4 for the entire scale leading to an I-CVI of 1. Qualitative comments demonstrated that content experts felt the scale should not use words like advance directives but rather "forms that plan my wishes at end of life". Negatively worded questions were also rejected by content experts. Content experts supported the pros and cons of illness but not the pros and cons of ADs. Content experts also rejected questions related to existential reflection. Suggestions for revisions in the existential reflection was to change to question 51 to "I can imagine a scenario where my illness or other conditions will cause my death". The item was rewritten to I can imagine a scenario where my illness will cause my death. The Flesch Kincaid Grade level was 6.8 with reading ease of 67.8 and ultimately this did not change reading ease of the total scale. The original 53 question APPS S-CVI was .83. The revised 36 question S-CVI was .94.

Table 2 demonstrates the I-CVI scores and items that were revised or removed.

Table 2

I-CVI Scores

Question #	*Relevance*	*Status*	***Question #***	*Relevance*	*Status*
1	.82	*kept*	*26*	*.64*	*removed*
2	.91	*kept*	*27*	*.91*	*kept*
3	1.00	*kept*	*28*	*1.0*	*kept*
4	1.00	*kept*	*29*	*.73*	*removed*
5	1.00	*kept*	*30*	*1.0*	*kept*

Question #	*Relevance*	*Status*	***Question #***	*Relevance*	*Status*
6	1.00	*kept*	*31*	*.64*	*removed*
7	.82	*kept*	*32*	*.64*	*removed*
8	.73	*Remove*	*33*	*.64*	*removed*
9	.91	*kept*	*34*	*.82*	*kept*
10	.82	*kept*	*35*	*.91*	*kept*
11	.64	*Remove*	*36*	*.73*	*removed*
12	.91	*kept*	*37*	*.73*	*removed*
13	*1.0*	*kept*	*38*	*1.0*	*kept*
14	*1.0*	*kept*	*39*	*.91*	*kept*
15	*1.0*	*kept*	*40*	*.91*	*kept*
16	*.55*	*removed*	*41*	*1.0*	*kept*
17	*.82*	*kept*	*42*	*.55*	*removed*
18	*.73*	*removed*	*43*	*1.0*	*kept*
19	.91	*kept*	*44*	*1.0*	*kept*
20	1.00	*kept*	*45*	*.64*	*removed*
21	.91	*kept*	*46*	*1.0*	*kept*
22	1.00	*kept*	*47*	*1.0*	*kept*
23	.55	*removed*	*48*	*.73*	*revised*
24	.81	*kept*	*49*	*.64*	*removed*
25	.73	*removed*	*50*	.81	*kept*
			51	.55	*Revised*
			52	*.64*	*removed*
			53	.81	*kept*

Table 3 compares the original relevance and average total S-CVI scores of the original and revised APP scale and the subscales.

Table 3

S-CVI Scores

Subscale	*Relevance Total*	*Average Total*	*Relevance Revised*	*Average Revised*
Psychological comfort with ACP	*13.56*	*.90*	*12.19*	*.94*
Desire to Know (Knowledge)	*12.29*	*.82*	*8.36*	*.93*
Thinking	*8.93*	*.81*	*5.55*	*.93*
Willingness	*5.19*	*.86*	*4.00*	*1.00*
Existential Reflection	*4.18*	*.84*	*5.62*	*.90*
Entire APP Scale	*44.15*	*.83*	*35.72*	*.94*

Table 4 lists all the questions removed.

Table 4

Questions Removed

Psychological comfort with advance care planning	
8	I would feel uneasy to talk about an end-stage disease with my health care team
11	I feel comfortable talking about how long I have to live.
Desire to know	
16	I prefer to discuss advance care planning when I first get diagnosed with a serious illness.
18	I need to know about advance directives
23	I want to know if I have an illness that is life threatening
25	I want to know about options to limit intensive care at end of life
Thinking	
31	I don’t want to think about an end-of-life talk with my provider
32	I have weighed quantity versus quality of life
33	I have thought about the pros and cons of having an advanced directive
36	I have thoughts that my illness will not get better
37	I have thought about having an advance directive
Willingness	
42	I am not willing to engage in advance care planning
45	I am not willing to talk about health care issues related to end of life
Existential Reflection	
49	I do not have a condition that will cause my death
52	I am peaceful when reflecting about the end of my life

Table 5 demonstrates the revised APPS scale that was utilized for pilot and full testing.

Table 5

Revised APPS Scale

Psychological comfort with advance care planning	
1	I would feel uneasy if someone talked to me about end-of-life planning
2	I feel comfortable thinking about topics related to end-of-life.
3	I find it easy to talk about end-of-life related health care.
4	I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.
5	I feel ready to discuss who should make health care decisions for me if I am unable to.
6	I feel okay when talking about planning for health care related to end of life.
7	I am ready to make decisions about end-of-life health care ahead of time
8	I prefer to make an advance directive when I am healthy
9	I feel at ease when saying my feelings about getting sicker
10	I feel ease with being asked about the things that are important to me
11	I am comfortable with discussing my wishes at the end of life
12	I am open to discuss my emotions about a decline in my health
13	I feel comfortable with discussing my health care choices at the end of life

Desire to know	
14	I desire to know more about advance care planning
15	I want to know the choices about treatments at the end of my life
16	I want to know the nature of the medical problems I have
17	I desire facts about my health to help me make my own end of life decisions
18	I prefer to discuss the pros and cons of CPR at end of life
19	I want to know about a condition that will cause my imminent death
20	I need knowledge about illnesses that are life threatening
21	I want to have knowledge about a condition that will cause my death
22	I prefer to have the true facts about whether my illness is terminal
23	I want to know what an advanced directive is
24	I want to know the odds that I may lose ability to make my own health care choices.
Thinking	
25	I have thought about my illnesses getting worse.
26	I have thought about what I would want when I get really sick
27	I think about the things I still want to do in this life.
28	I think about my preferences for end-of-life care
29	I have thoughts about people I value
30	I think about my values I want to maintain at the end of life
Willingness	
31	I am willing to say my wishes ahead of time about limits to care at end of life
32	If asked to, I will discuss my end of life wishes with my health care team
33	I am willing to talk about my illness with family that are dear to me
34	I am willing to talk about my end of life with my doctors and nurses
Existential Reflection	
35	I have an illness that is life threatening
36	I want to focus on the meaning of life when I approach the end of life
37	I have imagined a scenario where my illness will cause my death
38	I am satisfied with the meaning I have given to my life

Pilot Study

An initial pilot study was deployed August 16, 2022, and erroneous branching logic screened for experience with ACP during the first 48 hours. This error led to the exclusion of 7 participants who consented to the study. Of the initial 8 respondents, only one had experience with ACP. This single respondent reported heart failure. In addition, demographic questions were adjusted to reflect appropriate display logic. A demographic question was also added to stratify results between participants who had ADs versus those who did not. The pilot study was then redeployed ion August 21st through August 31st.

Pilot Descriptive Statistics

The pilot study questionnaire received 316 respondents of which 197 met criteria for chronic illness (62.3% eligibility rate). Of the 177 participants who read the consent, a total 173 participants consented to the study (98.3 % consent rate). After completing the thirty demographic questions, 119 participants participated in the pilot of which 93 surveys were completed that met inclusion criteria (78.2% retention rate). The 16 participants that contributed to the 21.9% attrition rate were similar to the final sample. No statistical difference existed in health status, perception of mortality, race, or gender. After cleaning 3 potential robots and removing 2 duplicates, 88 responses were prepared for data analysis.

The racial composition of the sample was white (n=70), black or African American (n=5), Asian (n=4), American Indian or Alaska Native (n=1) and multiracial (n=7). Ethnically, 42% of the sample was Hispanic (n=37). Several chronic illnesses were represented in the pilot sample including cardiac disease (n=40), cancer (n=17), diabetes (n=48), kidney failure (n=26), COPD (n=18), stroke (n=24) and other illness (n=11). Individuals described their health status as relatively healthy (n=46), having an illness treated chronically (n=24), having an illness that will go away in 90 days (n=11), seriously but not terminally ill (n=5) and seriously and terminally ill (n=2).

The pilot sample was predominantly married (n=65), employed (n=82) and 25-34 years old individual (n=41). The sample included 18-24 years old (n=10), 35-44 years old (n=24), 45-54 years old (n=5), 55-64 years old (n=5) and 65 years and older (n=2). The sample was also predominantly male (n=49) versus female (n=39). In addition, 47 participants were health care providers (HCPs) including social workers (n=20), physicians (n=13), physician assistants (n=8), registered nurses (n=5) and a licensed practical nurse (n=1). Of the health care providers (n=85), most had performed advance directives. The 85 HCPs participated in EOL care daily (n=15), weekly (n=26) and monthly (n=3). Predominantly the HCPs worked in home health care (n=26) with hospital settings (n=9) as the other highest work location. Primary units in the hospital included EDs (n=3), ICUs (n=3) and palliative care (n=2).

The pilot sample was comprised of multiple religious affiliation, Catholic (n=41), Christian (n=31), Baptist (n=2), Muslim (n=3), Jewish (n=2), Hindu (n=5), Atheist (n=2) and Agnostic (n=1). Twelve individuals reported that their religious affiliation effected their EOL decisions while most (n=40) reported that religion may affects their EOL decisions. Additionally, many participants (n=35) reported that religion did not affect their EOL decisions. The sample were parametrically represented by perception of longevity of life. Individuals perceiving less than 6 months to live were 12% of the sample followed 17.6% reporting 6-12 months to live, 19.8% reporting greater than 12 months to live, 29.7 % greater than 24 months to live and 2.9% reporting uncertainty in regard to their mortality.

The pilot participants were experienced with advance care planning. Forty-three participants had experienced the death of a person close to them in the past 2 years. Most had an EOL conversations with HCPs before (n=52) and had completed MOLST forms (n=41). Yet, most lay persons had never heard about advance directives (n=35). When asked about intent to complete an AD in the next six months, most (n=64) said likely with 14 stating very likely and 8 participants not likely.

Pilot Scoring of APPS

Of these 88 participants, the APPS scale was completed on average in 92.24 seconds (range of 22.02 seconds -737.34 seconds with a SD 121.02 seconds). The median completion time of the APPS was 59.94 seconds. Arrangement and acceptability were evaluated by 84 participants. The number of questions on each page was deemed acceptable (n=71). The arrangement of the items was deemed acceptable (n=66). Clarity was evaluated by 70 of the participants. Nine participants felt the instructions were probably not clear with 6 participants stating the wording of the items were probably not clear. Suggestions were to consider the order of the items as well and two participants remarked that AD can be reviewed multiple times. Others marked that they felt the question stems were leading and questioned why a durable power of attorney was not included in the survey. One participant suggested a brief description of the terms utilized. Missing responses did not occur in the pilot due to the response settings. However, participants did remark that carelessness had led to a response that needed to be reviewed. Moreover, 69 of 84 participants reported that items had the potential to be missed. Two questions in the psychological comfort domain were mentioned as uncomfortable by three participants; “I find it easy to talk about end-of-life related health care.” and “I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.” The pilot demonstrated the APPS was feasible and forced completion was continued to be utilized on the APPS survey. The two items were analyzed and kept for further evaluation in the full study.

Preliminary principal component analysis (PCA) produced the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy .883 with a $p < .001$. This indicated that there were adequate the correlations for factor analysis. As a general heuristic (Kaiser, 1970, 1974), a value of .70 or above is considered adequate. Although a small sample size, the Cronbach’s α was .961 for the 38-item scale and the type C intraclass correlation coefficient was significant with a p value =.000. Only if item #1 were deleted would Cronbach’s α increase to .966.

Inter-item correlation matrix revealed item #5 “I feel ready to discuss who should make health care decisions for me if I am unable to” was 65.7% correlated with item, # 9 “I feel at ease when saying my feelings about getting sicker”. Inter-item correlations mean was .422 (range .069 -.678) with a variance .11. Inter-item covariances mean was .343 (range .058-.562) with a variance of .008.

The minimal and maximal ratings for each item of APPS are 1 and 5 respectively with 5 indicate strongly agree. For the initial pilot survey, the average item ratings range from 3.71 to 4.1. The average scores of each subscale and the entire scale are presented in Table 6.

Table 6

Average Scores for APPS & Subscales

Subscale		***Average Mean***	***SD***
Psychological comfort with advance care planning		***3.96***	***.61***
1	I would feel uneasy if someone talked to me about end-of-life planning (Reverse Coded)	3.72	1.028
2	I feel comfortable thinking about topics related to end-of-life.	3.94	.889
3	I find it easy to talk about end-of-life related health care.	3.98	.884
4	I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.	3.92	.913
5	I feel ready to discuss who should make health care decisions for me if I am unable to.	3.93	.868
6	I feel okay when talking about planning for health care related to end of life.	3.90	.898
7	I am ready to make decisions about end-of-life health care ahead of time	3.97	.915
8	I prefer to make an advance directive when I am healthy	3.97	.976
9	I feel at ease when saying my feelings about getting sicker	4.07	.855
10	I feel ease with being asked about the things that are important to me	4.10	.923
11	I am comfortable with discussing my wishes at the end of life	3.97	.85
12	I am open to discuss my emotions about a decline in my health	3.99	.941
13	I feel comfortable with discussing my health care choices at the end of life.	4.02	.971
Desire to know		***3.99***	***.611***

14	I desire to know more about advance care planning	3.91	.930
15	I want to know the choices about treatments at the end of my life	4.05	.921
16	I want to know the nature of the medical problems I have	3.97	.903
17	I desire facts about my health to help me make my own end of life decisions	3.99	.851
18	I prefer to discuss the pros and cons of CPR at end of life	3.98	.897
19	I want to know about a condition that will cause my imminent death	3.97	.928
20	I need knowledge about illnesses that are life threatening	3.98	.959
21	I want to have knowledge about a condition that will cause my death	3.95	.946
22	I prefer to have the true facts about whether my illness is terminal	3.99	.916
23	I want to know what an advanced directive is	4.08	.861
24	I want to know the odds that I may lose ability to make my own health care choices.	4.08	.820
Thinking		***3.95***	***.637***
25	I have thought about my illnesses getting worse.	3.92	.861
26	I have thought about what I would want when I get really sick	3.92	.962
27	I think about the things I still want to do in this life.	4.01	.851
28	I think about my preferences for end-of-life care	3.91	.942
29	I have thoughts about people I value	4.01	.877
30	I think about my values I want to maintain at the end of life	3.95	.934
Willingness		***4.01***	***.655***
31	I am willing to say my wishes ahead of time about limits to care at end of life	3.97	.765
32	If asked to, I will discuss my end of life wishes with my health care team	4.05	.934
33	I am willing to talk about my illness with family that are dear to me	4.06	.764
34	I am willing to talk about my end of life with my doctors and nurses	3.97	940
Existential Reflection		***3.95***	***.677***
35	I have an illness that is life threatening	3.83	.874
36	I want to focus on the meaning of life when I approach the end of life	4.00	.858
37	I have imagined a scenario where my illness will cause my death	3.90	1.062
38	I am satisfied with the meaning I have given to my life	4.08	.900

Cronbach's α was .962 and as aforementioned would only increase to .966 with the removal of item #1. Only item # 1 indicated a negative Cronbach's α requiring the reverse coding. The scale statistical total score mean is 149.53 with a standard deviation of 22.1.

Full Study

The full study was deployed from August 24th, 2022, through November 7th, 2022. A total of 1015 participants responded to the full study survey. Participants were eligible when aged 18 years are older, understood English with simple mathematical literacy. Recruitment was completed using Amazon M-Turk, Reddit, flyers, community visits or social media. Eligible participants were provided a link to Qualtrics survey via email or QR code. A total of 781 participants met criteria for chronic illness and age over 18 years. Of the participants who met inclusion criteria, 86% reported experience with ADs. A total of 688 participants consented to complete the study with 527 participants completing the APPS survey and 475 participants completing all surveys.

Analysis of the non-completers revealed that they spent an average of 6.11 minutes on the survey with a range of 3 seconds to 116.8 hours. Of those that completed demographic data; the non-completers were 32.8% (n=17) female, 27% (n=14) male, 46.7% (n=24) married, 12.5 (n=7) % single, 1% (n=5) widowed; 41.1% (n=21) baccalaureate; 13.4 % (n=7) masters; 56.2% (n=29) employed; 22% (n=11) Hispanic; 29% (n=15) health care professionals and 35% (n=18) with chronic illness (heart failure, cancer, diabetes, kidney failure and COPD).

After the removal of duplicates and robots, a total of 455 completed surveys were combined with the 88 pilot participants for a total of 543 surveys analyzed in the full study. The mean duration for the completion of the survey was 5491.76 seconds (91.52 minutes) with a median of 745 seconds (12.42 minutes). The APPS survey was completed on average in 92.47 seconds with a median of 59.72 seconds and a standard deviation of 106.32 seconds.

Normality was examined by skewness, kurtosis, histogram, Q-Q plot, and Kolmogorov-Smirnov test of normality. The APPS was normally distributed. Box plot and Stem-leaf plot analysis revealed extreme cases in APPS in a range of .55% to 5% of the sample. Among the items with extreme cases in the *Psychological comfort with advance care planning* scale and included:

- "I find it easy to talk about EOL related health care" n=9.
- "I feel at ease to discuss the pros and cons of life sustaining treatment" n=11
- "I feel ready to discuss who should make health care decisions for me" n=12
- "I feel okay when talking about planning for health care related to EOL" n=5
- "I prefer to make an AD when I am healthy" n=28
- "I feel at ease when saying my feelings about getting sicker" n=11
- "I am comfortable with discussing my wishes at the EOL" n=7

Among the items with extreme cases in the *Desire to Know* scale and included:

- "I want to know the nature of the medical problems I have" n=25
- "I desire facts about my health to help me make my own EOL plans" n=30
- "I want to know about a condition that will cause my imminent death" n=6
- "I want to know the odds that I may lose ability to make my own health decisions" n=23

Among the items with extreme cases in the *Thinking* scale and included:

- "I have thought about my illnesses getting worse" n=7
- "I think about the things I still want to do in this life" n=4
- "I have thoughts about people I value" n=23

Among the items with extreme cases in the *Willingness* scale and included:

- "I am willing to say my wishes ahead of time about limits to care..." n=6
- "I am willing to talk about my illness with family that are dear ..." n=10

Among the items with extreme cases in the *Existential Reflection* scale and included:

- "I have an illness that is life threatening." n=15
- "I have imagined a scenario where my illness will cause my death" n=12
- "I am satisfied with the meaning I have given to my life" n=26

The full demographics of the participants are listed in Table 7. The sample was predominantly young with 68.2% of the sample between ages 18 and 34 years old. Only 28% of the sample perceived themselves with chronic illness despite nearly 52% of respondents having a MOLST. In addition, most participants were married (75.5%), experienced with ACP (89.3%), educated with a baccalaureate degree or higher (88.8%) and employed (92%). Health care providers marked 45% of the participants represented mainly by social workers (26%) with majority work location in home health care (26%). Catholicism and Christianity were the predominant religions represented (55% and 20% respectively). Thirty-four percent of the sample reported religion had no effect on their EOL decisions.

Over half of the participants experienced the death of a loved one in the past two years (56.5%) and reported knowledge and completion of all ADs (living wills, HCPs and MOLSTs). Yet only 24% of participants reported learning about ADs from HCPs and less than 5% of participants indicated that they were "very likely" to complete an AD in 30 or 180 days. Demographics are displayed in Table 7.

Table 7

Demographic Characteristics of the Full Study Sample

Characteristic	n	%	Characteristic	n	%
Age			Education Level (7)		
18-24 yrs.	84	15.5	< High School	6	1.1
25-34 yrs.	286	52.7	HS or equivalent	13	2.4
35-44 yrs.	94	17.3	Some college	24	4.4
45-54 yrs.	48	8.8	Associate degree	16	2.9
55-64 yrs.	24	4.4	Bachelor's degree	343	63.2
65+ yrs.	7	1.3	≥ Master's degree	135	24.9
AD/ACP Exp.[1]			Gender		
Yes	485	89.3	Male	253	46.6
No	33	6.1	Female	287	52.9
Unsure	25	4.6	Other[2]	3	.6
Marital			Employed		

Characteristic	n	%	Characteristic	n	%
Single	120	22.1	Yes	500	92.1
Married/Partnership	410	75.5	No, unemployed	33	6.1
W-D-S[3]	12	2.1	No, retired	1	0.2
Live Alone					
No	398	73.3			
Yes	129	23.8			
Race/Ethnicity			Chronic Illness		
Hispanic	145	26.7	None	7	1.4
White	494	91	Cancer	123	22.7
Black or AA[4]	29	5.3	Diabetes Mellitus	300	55.2
AI/AN[5]	24	4.4	Kidney Failure	108	19.9
Asian	34	6.3	COPD	87	16
PI/H[6]	15	2.8	Stroke	137	25.2
Multiracial	19	3.5	Cardiovascular	213	39.2
Other	3	0.6	Heart Failure	120	22.1
Health Care Provider	246	45.3	HCP Performed AD30[8]	277	
RN/APRNs/LPN[7]	30	5.5	Not at all	6	1.1
Physician Assistant	71	13.1	Every Day	103	19
Physician	55	1.1	Once per Week	103	19
Social Worker	131	24.1	Weekly	45	8.3
Other	3	.6	Once per month	20	3.7
HCP Work setting			Religion		
Primary Clinic	21	3.9	Agnostic	12	2.2
Academic University	43	7.9	Atheist	21	3.9
Long Term Care	15	2.8	Buddhist	12	2.2
Hospice	4	0.7	Catholic	299	55.1
Home Health Care	142	26.2	Hindu	37	6.8
Emergency Dept	16	2.9	Jewish	8	1.5
Intensive Care Unit	16	2.9	Muslim	17	3.1
Palliative Care Unit	10	1.8	Protestant	13	2.4
General Medical Unit	14	2.6	Jehovah Witness	2	.4
Surgical Unit	1	0.2	Other	8	1.6
			Baptist	5	0.9
			Christian, not listed	108	19.9
Religion-EOL choice[9]			SS at EOL[10]		
Yes	102	18.8	No	106	19.5
No	187	34.4	I don't know	102	18.8
Maybe	241	44.4	Yes	333	61.3
ClosPerson Died2years[11]			Knowledge of an AD		
No	233	42.9	No	216	39.8
Yes	307	56.5	Yes	325	59.9

Characteristic	n	%	Characteristic	n	%
Have an AD			Received info about AD		
No	109	2.1	No	231	42.5
Yes	267	49.2	Yes	309	56.9
Unsure	76	14.0			
AD intent in 30 days			AD intent in 180 days		
Very Likely	23	14.6	Very Likely	27	5
Likely	98	62.4	Likely	135	24.9
Not at all Likely’	36	22.9	Not at all Likely’	34	6.3
Discussed AD with HCP	177	32.6	Discussed EOL with HCP	191	35.2
No	353	65	No	344	63.4
Yes			Yes		
Know Healthcare Proxy			Have Healthcare Proxy		
Yes	365	67.2	Yes	313	57.6
No	171	31.5	No	184	33.9
Know Living Will			Have a living will		
Yes	399	73.5	Yes	331	61
No	134	24.7	No	183	33.5
Know MOLST			Have MOLST*		
Yes	324	59.7	Yes	280	51.6
No	211	38.9	No	219	40.3
Written Instruct[12]			Verbal Instruct[13]		
Yes	336	61.9	Yes	354	65.2
No	198	36.5	No	183	33.7
Current Health Status			AD Information Source		
Relatively healthy	242	44.6	Healthcare Provider	133	24.5
Healing in 90 days	101	18.6	Family Member	124	22.8
Chronic illness	152	28.0	Friend	82	15.1
Serious not terminal	33	6.1	Social Media/internet	114	21.0
Serious and terminal	14	2.6	Other	5	0.9
Remaining Life					
Less than 6 months	51	9.4			
6-12 months	105	19.3			
More than 1 year	115	21.2			
More than 2 years	166	3.6			
Uncertain	105	19.3			

Notes: *Have MOLST-52% of sample noted by clinicians to have less than 1-2 years of life

Abbreviations

[1] AD/ACP Exp. = Experiences with advanced directive or advance care planning.

[3] W-D-S = Widowed, divorced and separated with 4 participants in each category.

[3] Other gender include Transgender (1), Nonbinary (1) and Nondisclosed (3)

[4] AA = African American

[5] AI/AN = Amer Indian or Alaskan Native

[6] PI/H = Pacific Islander/ Hawaiian
[7] RN/APRN/LPN = Registered Nurses or Advance Practice RN or Licensed Practice Nurse
[8] HCP Performed AD30 = If a healthcare provider, frequency of performing advanced directive in the last 30 days.
[9] Religion-EOL choice = Does religion affect your choice of end-of-life care?
[10] SS at EOL = Do you have someone to support you at end of life?
[11] ClosPerson Died2years = Death of a close person in past two yrs.
[12] Written Instruct = Written Instructions about treatments if one is unable
[13] Verbal Instruct =Verbal Instructions about treatments if one is unable

The deidentified data was screened, cleaned, and prepared for the data analysis. For the deployed APPS, no missing data were identified for the 543 participants. The minimal and maximal ratings for each item of APPS are 1 and 5 respectively with 5 indicating strongly agree. Item 1 is negatively worded and thus reverse coding was utilized. For the full survey, the average item ratings range from 2.31 to 4.06. Question 1 performed differently in the full study as evidence by the mean and standard deviation. The average scores of each subscale and the entire scale are presented in Table 8 below.

Table 8

Average Scores of APPS and Subscales

Subscale		***M***	***SD***
Psychological comfort with advance care planning		***3.77***	***.551***
1	I would feel uneasy if someone talked to me about end-of-life planning (Reverse Coded)	2.31	.975
2	I feel comfortable thinking about topics related to end-of-life.	3.90	.915
3	I find it easy to talk about end-of-life related health care.	3.84	.903
4	I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.	3.85	.919
5	I feel ready to discuss who should make health care decisions for me if I am unable to.	3.85	.924
6	I feel okay when talking about planning for health care related to end of life.	3.89	.870
7	I am ready to make decisions about end-of-life health care ahead of time	3.90	.898

8	I prefer to make an advance directive when I am healthy	3.98	.854
9	I feel at ease when saying my feelings about getting sicker	3.86	.892
10	I feel ease with being asked about the things that are important to me	3.95	.920
11	I am comfortable with discussing my wishes at the end of life	3.85	.887
12	I am open to discuss my emotions about a decline in my health	3.88	.953
13	I feel comfortable with discussing my health care choices at the end of life.	3.91	.910
Desire to know		***3.94***	***.581***
14	I desire to know more about advance care planning	3.92	.903
15	I want to know the choices about treatments at the end of my life	3.93	.862
16	I want to know the nature of the medical problems I have	4.02	.854
17	I desire facts about my health to help me make my own end of life decisions	3.90	.831
18	I prefer to discuss the pros and cons of CPR at end of life	3.94	.948
19	I want to know about a condition that will cause my imminent death	3.85	.871
20	I need knowledge about illnesses that are life threatening	3.97	.926
21	I want to have knowledge about a condition that will cause my death	3.92	.858
22	I prefer to have the true facts about whether my illness is terminal	4.00	.861
23	I want to know what an advanced directive is	3.96	.876
24	I want to know the odds that I may lose ability to make my own health care choices.	3.98	.832
Thinking		***3.91***	***.637***
25	I have thought about my illnesses getting worse.	3.86	.849
26	I have thought about what I would want when I get really sick	3.91	.915
27	I think about the things I still want to do in this life.	3.89	.827
28	I think about my preferences for end-of-life care	3.88	.913
29	I have thoughts about people I value	3.98	.836
30	I think about my values I want to maintain at the end of life	3.98	.866
Willingness		***4.01***	***.655***

31	I am willing to say my wishes ahead of time about limits to care at end of life	3.91	.801
32	If asked to, I will discuss my end of life wishes with my health care team	3.92	.880
33	I am willing to talk about my illness with family that are dear to me	3.93	.852
34	I am willing to talk about my end of life with my doctors and nurses	3.96	.940
Existential Reflection		***3.90***	***.677***
35	I have an illness that is life threatening	3.79	.874
36	I want to focus on the meaning of life when I approach the end of life	3.92	.858
37	I have imagined a scenario where my illness will cause my death	3.84	1.062
38	I am satisfied with the meaning I have given to my life	4.06	.900

Full Study Scoring of APPS

Item response theory using R integration was utilized to examine the latent trait of preparedness. In the full study, the extended RASCH model was utilized to estimate the levels of the latent traits of the participants, and to evaluate how well the items, individually and collectively, measure the test subject's latent trait. The extended RASCH model performed better than the pilot study. In the full study, reviewing Wald test for Item elimination, Item # 1R again had a statistically significant p value less than < .009 for all choices. In addition, the item thresholds indicated Item IR was overdiscriminating and it loaded on an additional latent variable not centering around other items. The location of the item threshold for item 1 was only 2.603 and the only item demonstrating a threshold greater than 1.

As in the pilot study, reliability was high Cronbach's α was .954. All cases were valid and not excluded. Item means was 3.87 with a range of 2.31 through 4.06 and a variance of .071. Inter item covariances was .273 (range –.353 through .460) and inter item correlations was .351 (range –.407 through .567). Only the removal of item #1 would increase the Cronbach's α to .958. The mean score of the scale was 147.14 with a SD 2.36 and a variance of 414.42. In addition, the removal of Item 1 in the psychological comfort scale would increase Cronbach's α from .856 to .897. Table 9 displays the Cronbach α, mean score and SD for the APPS scale and subscales

Table 9

Cronbach's α Coefficients for Full Study vs Retest

Scale/Subscale	Initial Test (N=543)		Retest (n=92)	
	Cronbach α	M (SD)	Cronbach α	M (SD)
APPS Full Study	.954	147.14 (2.36)	.946	146.79 (18.03)
♦ *Psychological comfort*	.856*	48.97* (7.16)	.871	49.03 (6.99)
♦ *Desire to know*	.873	43.36 (6.39)	.807	43.39 (4.98)
♦ *Thinking*	.776	23.49 (3.58)	.692	23.40 (3.04)
♦ *Willingness*	.740	15.71 (2.58)	.723	15.57 (2.47)
♦ *Existential Reflection*	.652	15.62 (2.52)	.580	15.40 (2.36)

Test-Retest Reliability of APPS

Participants were surveyed on average 72 hours after their full study response. Response rates were significantly diminished with only 9% of the full study agreeing to retest. Allowing participants who agreed to retest to view the retest survey link upon completion of the initial study was then deployed. In total only 97 participants participated in the retest. After removal of duplicates a total of 92 participants responses were analyzed. The average completion of APPS on the retest was 3.22 minutes with a range of 1 to 15.60 minutes.

The retest participants were assessed for life events. They reported, that in the past 2 days prior to the retest, 78% (n= 72) answered they suffered a serious illness, injury, or assault. And 64% (n= 59) reported a relative had also had a serious illness, injury, or assault. Forty-seven percent reported losing their job (n= 43) and 65% (n=60) reported the death of someone close to them. The reliability of the retest was also adequate despite the small sample size.

The Cronbach's α was .946 and would increase to .949 with the removal of item #1. Mean score utilizing CTT was 146.79 with a SD 18.03.

Test-retest reliability was assessed utilizing intraclass correlation coefficients (ICC) with a two-way mixed model of absolute agreement. For the entire APPS the Cronbach's alpha was .960 with a Type A intraclass correlation of average measures at .954 (95% CI .94-.967) [F (88,660) = 24.37, p <.001]. For the single measures Items #1 and #2 violated reliability model assumptions and had single measure intraclass correlations that were nonsignificant and negative (-.512 and –.704) respectively. In addition, item # 10 "I feel ease with being asked about the things that are important to me" and #20 "I need knowledge about illnesses that are life threatening" had nonsignificant ratings. Regarding the participants in the retest, participants were younger with 80% under the age 34. On retest, Cronbach's α of the subscale average measures ranged from .773 to .902 demonstrating reliability between the subscales on retest. Assumptions are limited due to the small sample size and the large number of retest participants who reported significant life events. Table 10 shows the test-retest reliabilities when participants who reported significant life were included and excluded.

Table 10

Test-Retest Intraclass Correlation Coefficient of Subscales

Subscale	n	Initial Test M (SD)	M(SD) Re-Test	ICC (95%CI) Test Sig <.001	ICC (95%CI) Retest Sig <.001
APPS	89	3.86 (.686)	3.86 (.603)	.946 (.927-.960)	.740 (.629-.821)
Psychological comfort	89	3.74 (.431)	3.77 (.538)	.816 (.72-.879)	.689 (.562-.784)
Desire to know	89	3.96 (.447)	3.94 (.452)	.788 (.677-.861)	.650 (.511-.756)
Thinking	89	3.86 (.560)	3.90 (.505)	.715 (.567-.813)	.556 (.395-.684)

Willingness	89	3.90 (.648)	3.89 (.618)	.831 (.743-.889)	.711 (.591-.800)
Existential Reflection	89	3.87 (.529)	3.85 (.589)	.767 (.644-.847)	.621 (.475-.734)

Construct Validity: Exploratory Factor Analysis

An exploratory factor analysis (EFA) was performed using Principal component analysis (PCA) with Promax rotation. PCA with Promax rotation was chosen because there are significant correlations between factors (Table 11). Initial analysis revealed that item #1 hindered best solutions and was a significant outlier in all component matrices. Table 12 compares the Kaiser-Mayer-Olkin (KMO) values, Bartlett's test of sphericity, and total variance explained when item #1 was included and excluded. Thus, the following sections report the PCA results without item #1.

The scree plot (Figure 2) suggested the solution was either a 4- or 5-factor model. The 5-factor model was based on eigenvalue greater than 1, while the 4-factor model used a fixed number to extract factors.

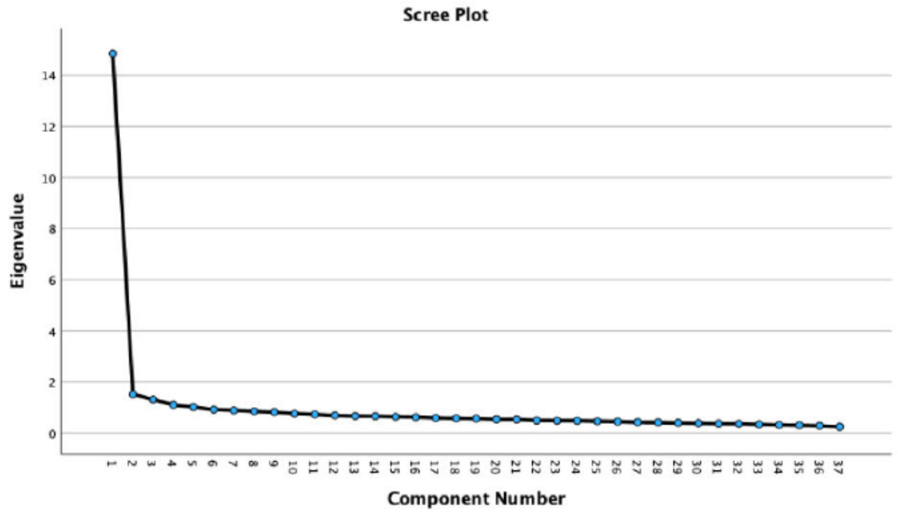


Figure 2: Scree Plot

The Kaiser-Mayer-Olkin measure of sampling adequacy was .967, and Bartlett's test of sphericity demonstrated significance (X^2 (666) =962.1, p<.001). Principal component analysis excluding item 1 delivered an improved 5 factor model that explained 53.5 % of the variance while the 4-factor model utilizing PCA explained 50.7% of the variance.

Table 11

Factor Component Correlation Matrix for the 4-factor Model

Factor	1	2	3	4
1	1.00	.560	.523	.556
2	.560	1.00	.603	.630
3	.523	.603	1.00	.638
4	.556	.630	.638	1.00

Extraction Method: Principal Component Analysis.
Rotation Method: Promax with Kaiser Normalization.

Table 12

KMO, Bartlett's test, and variance explained with or without Item 1

	5-Factor Model		4-Factor Model	
	With Item 1	Without Item 1	With Item 1	Without Item 1
KMO Test	.966	.967	.966	.967
Bartlett's test	$X^2(703)$ =9807.64, p<.001	($X^2(666)$ =962.1, p<.001).	$X^2(703)$ =9807.64, p<.001	($X^2(666)$ =962.1, p<.001).
Variance explained	52.8	53.5	50.0	50.7

Components of the 4-Factor Model

The results of the Promax rotation of the 4-factor solution are shown in Table 13. Loadings less than .30 were suppressed.

Table 13

Principal Component Analysis with Promax Rotation for the 4 Factor Model

APPS Item #	Component				
	Desire to Know	Psychological Comfort	Thinking	Willingness	Commonalities
25	.699				.57
17	.674				.57
33	.624				.58
29	.511				.50
37	.509				.39
21	.492				.46
27	.449				.43
31	.414				.48
19	.389			.346	.49
23	.348			.305	.40
3		.714			.53
7		.682			.56
9		.679			.56
11		.663			.58
13		.645			.53
35		.542	-.361		.46
4		.525			.53
2		.431	.413		.55
15		.423			.48
5	.304	.348			.44
10			.802		.63
26			.764		.58
34			.711		.60
18			.649		.55
6		.402	.419		.55
32			.360	.322	.45
14			.356	.352	.47
38		.329	.353		.48
28				.740	.54
20				.691	.50
36				.649	.52
8				.598	.54
16				.522	.51
22				.393	.40
24				.383	.48
12		.349		.368	.49

30	.307	.42

Factor loadings were reviewed and those at a high level to where theoretical factors were designated to, were analyzed to determine removal or retention of the item in its original domain. Eleven items achieved coefficients greater than .3 onto component 1. These items related to the “Desire to Know” subscale and included 17, 19, 21, 23, 25, 27, 29, 31, 33 and 37. Item 5 barely had a coefficient greater than .3 on component 1 and a similar cross-loading on component 2. Item 19 also has cross-loading on component 4 and the difference between the two factor loadings does not exceed .5. The pattern of the factor loadings included several items in the theoretical domain of thinking; items 6, 10, 14, 18, 26, 32, 34 and 38. Thinking and desiring to know are potentially correlated.

Thirteen items loaded onto the psychological comfort subscale; items 2-7, 9, 11-13, 15, 35 and 38. Theoretical factors related to existential reflection, item 38, cross loaded in this subscale and the thinking subscale with a diminished factor loading of .329. This prompted a review of the item.

Ten factors loaded onto the thinking subscale. Fifty percent of the loadings cross loaded similarly with decreased coefficients (.30 -.45) onto other factors. The factors included 2, 6, 10, 14, 18, 26, 32, 34, 35 and 38. Items 35 were negatively correlated and deemed not to remain in the subscale. Finally, 15 items loaded onto the factor deemed most closely to willingness. Items that loaded onto factor 4 included 8, 12, 14, 16, 19-24, 28-30, 32 and 36.

Several items appeared to load equally on multiple subscales. Nine items 2, 5, 6, 12, 14, 19, 23, 32 and 38 were loaded nearly equally on “desire to know” and “thinking”. Items in future study may need to be rewritten to aid in discrimination of the factors. For example, item #2 states “I feel at ease when thinking about health care topics related to end of life”. Although the item was in the psychological comfort scale it is equally loaded in the thinking subscale. Utilizing the PCA extraction, the subscales were reconfigured, and reliability assessed for the four-factor model (see Table 13).

The Psychological Comfort scale in the four-factor model included 2-5, 7, 9, 11, 13, 15 and 35. The “Desire to Know” scale included 17, 19, 21, 23, 25, 27, 29, 31, 33 and 37. The “Thinking” scale included 6, 10, 14, 18, 26, 34 and 38. The “Willingness” scale included 8, 12, 16, 20, 22, 24, 28, 30 and 36. Subscale correlations with the theoretical model subscales were not acceptable for the subscales of thinking (r=.798) and willingness (r=.765) however, each was significant with a p<.001. Analyzing the subscale of psychological comfort removing any item, including #35 would decrease its’ reliability. Desire to know, thinking and willingness would also not have improved reliability with the removal of any item. As shown in Table 14 the reliability of the PCA 4-factor model subscales were higher than the theoretical model subscales.

Table 14

Mean and Reliability for the Original Subscales and PCA 4-Factor Model

Subscale	N	Mean (SD)		Cronbach’s α	
		Original Subscale	PCA 4- Factor Model	Original Subscale	PCA 4-Factor Model
Psychological comfort	543	3.74 (.431)	3.87 (.627)	.856	.881
Desire to know	543	3.96 (.447)	3.90 (.586)	.873	.875
Thinking	543	3.86 (.560)	3.95 (.662)	.776	.855
Willingness	543	3.90 (.648)	3.96 (.611)	.740	.864
Existential Reflection			N/A		N/A

Ultimately the original design was not supported. The four-factor model demonstrated improved reliability. However, there was significant overlap as evidence by factor loadings demonstrating multiple cross loadings of variables on multiple factors. The commonalities indicated the need for continued search of a better model. As the 5-factor model explains more of the variance, it was also investigated for an improved model fit.

Five Factor Model

In the 5-factor model, the Promax rotation revealed the factors were correlated and the varimax method minimized the number of variables that had high loadings on each factor. Both solutions were reviewed comparatively utilizing PAF and PCA.

The initial extraction supported the theoretical structure of the five components of APPS; psychological comfort, desire to know, thinking, willingness and existential reflection. Pattern matrixes revealed cross loading in both extraction methods. The PAF extraction with Promax rotation and Kaiser normalization converged in 15 iterations and led to solution where items 5, 30 and 31 did not meet the .30 criterion as a loading coefficient threshold. The principal axis factoring method also had high component correlations when Promax was utilized as the rotation model. Principal axis factoring with varimax rotation and Kaiser normalization also converged in 15 iterations but led to a solution where 27 of the 37 items had cross loadings on multiple factors. In addition, absolute coefficients were low with the highest being .21.

Principal component analysis with varimax rotation and Kaiser normalization converged in 14 iterations but led to a solution where 32 of the 37 items had cross loadings on multiple factors. In addition, absolute coefficients were improved when compared to PAF but not as high when Promax rotation was employed. The factor component correlations were smaller than PAF when PCA was utilized as the extraction method with Promax rotation. Therefore, the 5 factor PCA model with Promax rotation and Kaiser normalization was utilized as it performed better than PAF.

Factor component correlations are shown below in Table 15. Moreover, as aforementioned the 5-factor model explained 53.48% of the variance (Table 16). Principal component analysis with Promax rotation demonstrated a high inter-relationship between the factors with significant correlations between factors (Table 17).

Table 15

Factor Component Correlation Matrix for the 5-factor Model

Factor	1	2	3	4	5
1	1.00	.593	.581	.471	.519
2	.593	1.00	.633	.469	.474
3	.581	.633	1.00	.496	.473
4	.471	.469	.496	1.00	.466
5	.519	.474	.473	.466	1.00

Extraction Method: Principal Component Analysis.
Rotation Method: Promax with Kaiser Normalization.

Table 16

Cumulative Variance Explained by 5-Factor Model

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings^a
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	14.85	40.13	40.13	14.85	40.13	40.13	10.60
2	1.52	4.10	44.22	1.52	4.10	44.22	10.73
3	1.31	3.54	47.76	1.31	3.54	47.76	10.17
4	1.10	2.97	50.73	1.10	2.97	50.73	8.18
5	1.02	2.75	53.48	1.02	2.75	53.48	8.29

Extraction Method: Principal Component Analysis.

a. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

Table 17

Principal Component Analysis with Promax Rotation for the 5 Factor Model

APPS Item #	Component					
	Psychological Comfort	Desire to Know	Thinking	Willingness	Existential Reflection	Commonalities
3	.700					.56
7	.667					.57
11	.647					.58
13	.634					.55
9	.628					.57
4	.517					.53
2	.42		.404			.56
15	.408					.48
38	.35					.50
5	.303					.48
16		.673				.60
8		.655				.57
28		.588				.56
20		.561				.51
36		.552				.52
12		.551				.57
24		.497				.51
22		.441				.41
32		.362				.45
30		.321				.43
26.			.863			.66
10			.742			.63
18.			.686			.58
34.			.582			.61
14.			.41			.50
6.	.396		.399			.52
17.				.702		.63
33.				.624		.61
25.				.604		.58
29.				.538		.58
31.				.32		.48

37.					.613	.52
19.					.596	.56
35.	.459				.496	.51
27.					.463	.46
23.					.402	.42
21.					.395	.47

Factor 1 identified as “Psychological comfort” loaded with 13 items; APPS numbers 2, 3, 4, 5, 6, 7,9, 11, 12, 13, 15, 35 and 38. Five of the items cross loaded onto multiple factors. Item APPS #12 Psychological Comfort loaded higher on Factor 2 “Desire to Know” than Factor 1 psychological comfort. Item #4 loaded higher on Psychological Comfort than Factor #2 Desire to Know. Items #2 and # 6 loaded with similarly equally coefficients on Factor 3 “Thinking”. Item 35 loaded slightly higher on factor 5 “existential reflection”.

Factor 2 identified as “Desire to know” loaded with 12 items; APPS numbers 4, 8, 12, 16, 20, 22, 24, 28, 29, 30, 32 and 36. Five of the items cross loaded onto multiple factors. As aforementioned items 4 and 12 loaded on Psychological Comfort as well. Items 20 and 28 cross loaded at a lower level on Factor 5 “existential reflection”. Item 29 cross loaded higher on Factor 4 “Willingness”.

Factor 3 identified as “Thinking” had 7 items; APPS numbers 2,6, 10, 14, 18, 26 and 34. Three of the items cross loaded onto multiple factors with higher loadings. Items 2 & 6 “psychological comfort” as previously mentioned loaded nearly equally in that factor subscale.

Factor 4 identified as “Willingness” had 6 items; APPS numbers 16, 17, 25, 29, 31 and 33. Items 16 and 29 cross loaded with Factor 2 “Desire to Know”. Items 16 and 31 barely met the criteria for .3 minimum coefficient.

Factor 5 identified as “Existential Reflection” had 8 items with three of the items loading on multiple factors. The factors included 19, 20, 21, 23, 27, 28, 35 & 37. Items 35 loaded slightly higher here than in Factor 1 “psychological comfort”. Items 20 and 28 loaded as priorly mentioned in Factor 2 “Desire to Know”.

Items # 2 and #6 cross loaded on psychological comfort and thinking. When reviewing these items, the wording of the items was confused between comfort with thinking and comfort with planning. When reviewing these items, the wording of the items was confused between comfort with thinking and comfort with planning. The items were removed from the 37-item scale and Cronbach’s α was .956 of the resulting 35 item scale. The removal of the additional items resulted in a Kaiser-Mayer-Olkin measure of sampling adequacy was .964. Similarly, Bartlett’s test of sphericity demonstrated significance ($X^2(595) = 8985.95$, $p<.001$). The revised 35 item scale explained 53.89% of the total variance.

Utilizing the factor loadings of PCA, the factors were reconfigured and compared to prior analysis. Psychological comfort was identified as the means of 9 items; 3, 4, 5, 7, 9, 11, 13, 15 and 38. Desire to know was identified as the means of 10 items; 8, 12, 16, 20, 22, 24, 28, 30,32, and 36. Thinking was identified as the means of 5 items; 10, 14, 18, 26, and 34. Willingness was identified as the means of 5 items 17, 25, 29, 31 and 33 Existential reflection was identified as the means of 6 items 19, 21, 23, 27, 35 and 37.

Utilizing the reidentified factors, the reliability of most subscales improved although willingness decreased from .864 to .82 The final Pearson r coefficients with the reconfigured subscales were all significant with a $p<.001$ and included psychological comfort ($r=.87$), desire to know ($r=.875$), thinking ($r=.842$), willingness ($r=.820$) and existential reflection ($r=.787$). The 5-factor model accounted for existential reflection with six items. As the existential reflection items are interdependent it accounts for the lower Cronbach alpha. Given the larger variance of the 5-factor model and similar reliabilities of the subscales, the 5-factor model will be utilized for confirmatory factor analysis (CFA). Table 18 displays the comparison of the revised 5 factor 35 item pool and the 4 factor 37 item pool.

Table 18

r Correlation Coefficient of APPS and Subscales with PCA Factors

Subscale	N	Mean (SD)		Cronbach Alpha	
		Original Subscale	PCA 5 Factor Model	PCA 4 Factor Model	PCA Revised 5 Factor Model
Psychological comfort	543	3.74 (.431)	3.89 (.626)	.881	.87
Desire to know	543	3.96 (.447)	3.95 (.610)	.875	.875
Thinking	543	3.86 (.560)	3.93 (.636)	.855	.84
Willingness	543	3.90 (.648)	3.91 (.636)	.864	.820
Existential Reflection	543	3.87 (.529)	3.87 (.613)	n/a	.787

Confirmatory Factor Analysis

A confirmatory factory analysis (CFA) was performed to evaluate the structure of the 5-factor model and model fit of the APPS. Confirmatory factor analyses were conducted to compare the two different second order models for the original theoretical model and the EFA model. The sample size for these confirmatory factor analyses is 543. Confirmatory factor analysis also served as a means of support for the exploratory factor analysis findings. The CFA involved 5 steps and are described hereafter in the next section (a) model specification, (b) model identification, (c) model estimation, (d) model evaluation, and (e) model re-specification. The CFA model will be performed for the original theoretical model and for the model constructed from the EFA.

Confirmatory Factor Analysis for Original Theoretical Survey Model

Model specification

The hypothesized 5-factor model based on the constructed survey is shown schematically in Figure 3. In the model, five latent variables, which are constructs of Advance Planning Preparedness are indicated by Psychological Comfort, Desire to Know, Thinking, Willingness and Existential Reflection. According to the original APPS model, there are 35 item variables: 10 measured variables to indicate psychological comfort, 11 measured variables to indicate desire to know, six measured variables to measure thinking, four measured variables to indicate willingness, and four measured variables to indicate existential reflection.

Model identification

To assess if the proposed theoretical model is identified, the model as shown in Figure 3 was constrained by fixing one factor loading parameter to a value of 1.00 for the latent factor and labeling five residual terms with equality constraints (Figure 3).

In the specified model shown below, the number of distinct sample moments were 630 and 75 distinct estimated parameters; (35 measurement errors, 35 observed and 45 unobserved) created 556 degrees of freedom. There were 192 total parameters; 81 variables, 35 directly measured variables, 35 measurement errors, 6 latent factors and 35 unobserved variables in the hypothesized APPS Scale.

Model estimation

The parameters were estimated using maximum likelihood method with bootstrapping. The factor loadings (the standardized weights) are shown in Figure 3, which range from .55 to

.71. All regression weights are statistically significant at 0.05 level and no S.E values were less than .07 or greater than .09.

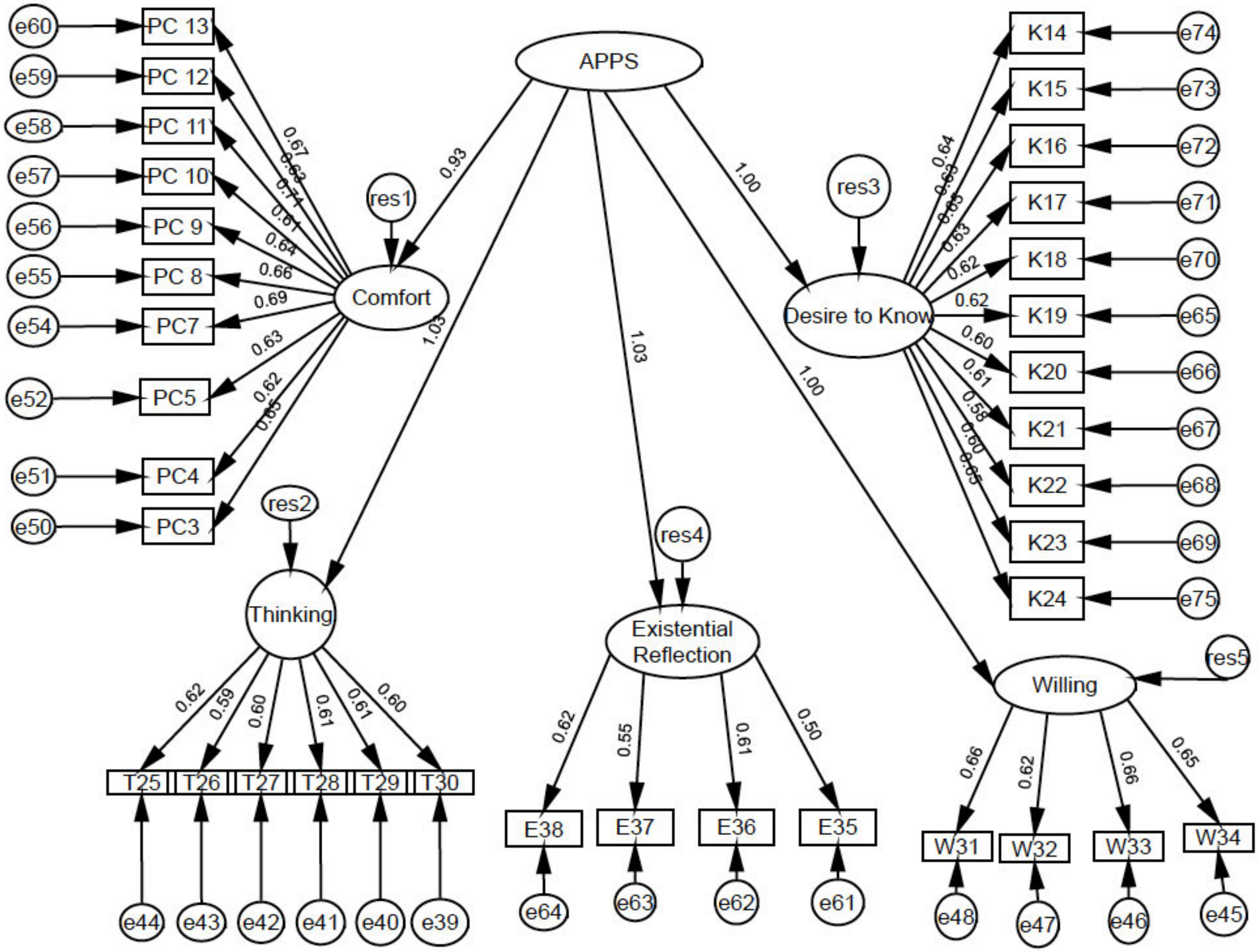


Figure 3: *Five Factor Second Order Theoretical APPS-35 Model with Correlations of Latent Variables Specified*

Model evaluation

The model was evaluated based on several fit indexes. This study was guided by the thresholds postulated by Schumacker & Lomax (2004) as well as Meyers et al. (2021). The (Non) Normed Fit Index (NFI) and Tucker Lewis Index (TLI) indicates the model of interest improves the fit and they should be greater than .95 (Schumaker et al., 2004). The Comparative Fit Index (CFI), and Incremental Fit Index (IFI) should be > .90. The CFI is a revised form of NFI and compares the fit of the proposed model to the fit of an independent (null) model while IFI adjust the NFI for sample size and degrees of freedom. The Root Mean Square Error of Approximation (RMSEA) a parsimony-adjusted index, should be < .08, with values closer to 0 representing a good fit. Like RMSEA should be < .08. The Parsimony-Adjusted Measures Index (PNFI) has no commonly agreed-upon cutoff value for an acceptable model but should be > 0.50.

The chi-square test for the theoretical model was statistically significant χ^2 (555) = 1580.3, p<.000, indicating that the model's covariance structure was significantly different from the observed covariance matrix. Due to the large sample size this was expected. The χ^2/df ratio is 2.85 indicating a good fit. The model fit indices are NFI = .828, IFI = .881, TLI =.872, CFI =.881, and RMSEA =.058, which showed the model was on the border of adequate fit. Standardized regression weights on willingness, thinking and existential reflection were slightly higher than 1. Thus, the model was incorrectly specified, and additional modifications were necessary to improve the fit.

Model modifications for Second Order Theoretical Model

Modification indices were utilized to improve the model by creating covariances between standard errors in the same latent variables. Covariances that led to a positive change in the model with modification indices greater than 10 were introduced to the model linking their unobserved errors (Table 20). Item #7 "I am ready to make decisions about end-of-life health care ahead of time" and Item #3 "I find it easy to talk about end-of-life related health care" was the largest par change to the model (M.I. 27.771 par change .107).

Based on these covariances, the model was respecified as shown in Figure 4. The new model created 5 covariance paths between unobserved errors in each of the factors. Table 19 compares the model fit indices before and after model modification and suggests a better fit of the final theoretical model than the original theoretical structure. The five factors appeared over specified with regression weights in existential reflection and thinking measuring 1.03. The model also included the largest correlations between measurement errors in different factors (M.I. 35.354 par change .011). This error was attributed to Thinking item #25 "I have thought about my illness getting worse" and Desire to Know item #17 "I desire facts about my health to help me make my own end of life decisions". The theoretical Second Order CFA did not demonstrate a robust model relating the latent variable to the constructs. The sample size was adequate thus fit indices BIC were utilized over AIC and BCC because the factor loadings in your model are greater than .5 (Burnham & Anderson, 2004; Vreize, 2012).

Table 19

Comparison of Model Fit Indices for Second Order Theoretical Structure

Model					Fit Indices					AIC	BIC
	$X^2 (p=.000)$										
	Value	*df*	X^2/df	*RMSEA*	*NFI*	*CFI*	*IFI*	TLI	PNFI		
Initial Model	1580.7	553	2.85	.058	.828	.881	.881	.872	.773	1730.3	2052.6
Respecified Model	1484.2	549	2.69	.056	.839	.891	.892	.882	.774	1646.2	1994.3

.

Note. RMSEA= root mean square error of approximation NFI= Normed Fit Index. CFI =Comparative Fit Index, IFI=Incremental Fit Index, TLI= Tucker Lewis Index, PNFI=Parsimony-Adjusted Measures Index

Table 20

Modifications Indices Covariances

Path in Same Factor	***M.I.***	***Par Change***
e71←→ e72	10.216	.060
e50←→ e54	27.771	.107
e39←→ e43	11.550	.074
e49←→ e53	14.253	.078
e 51←→ e55	12.610	.073
e71←→ e74	14.510	-.076
e63←→ e64	12.813	-.083

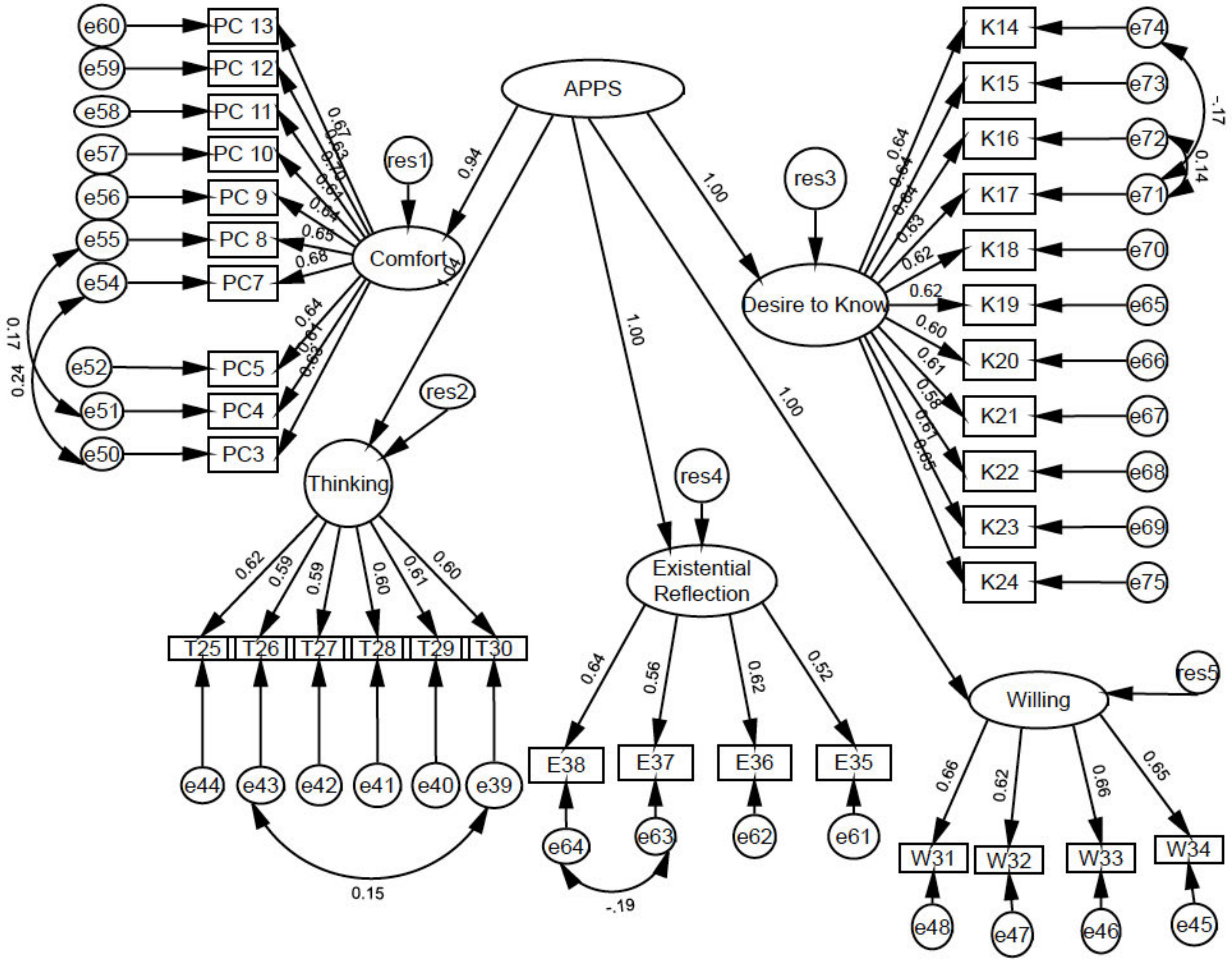


Figure 4: *Final Theoretical Model for 5 factor APPS Survey Original Structure*

Confirmatory Factor Analysis for APPS Survey Model Based on PCA

Model specification

The hypothesized 5-factor CFA model based on the factor loadings from the EFA utilizing PCA with Promax rotation is shown schematically in Figure 5. In the model, five latent variables, which are constructs of Advance Planning Preparedness are indicated by Psychological Comfort, Desire to Know, Thinking, Willingness and Existential Reflection. According to the APPS model based on PCA, there are 35 item variables: 10 measured variables to indicate psychological comfort, 10 measured variables to indicate desire to know, five measured variables to measure thinking, four measured variables to indicate willingness, and six measured variables to indicate existential reflection. Psychological comfort was identified as the means of 9 items; 3, 4, 5, 7, 9, 11, 13, 15 and 38. Desire to know was identified as the means of 10 items; 8, 12, 16, 20, 22, 24, 28, 30,32, and 36. Thinking was identified as the means of 5 items; 10, 14, 18, 26, and 34. Willingness was identified as the means of 5 items 17, 25, 29, 31 and 33 Existential reflection was identified as the means of 6 items 19, 21, 23, 27, 35 and 37.

Model identification

To assess if the proposed EFA model is identified, the model as shown in Figure 5 was constrained by fixing one factor loading parameter to a value of 1.00 for each of the five latent factors and labeling five residual terms with equality constraints (Figure 5). In the specified model shown below, the number of distinct sample moments were 630 and 75 distinct estimated parameters; (36 measurement errors, 35 observed and 46 unobserved) created 555 degrees of freedom. There were 204 total parameters; 81 variables, 35 directly measured variables, 36 measurement errors, 6 latent factors and 46 unobserved variables in the hypothesized APPS Scale.

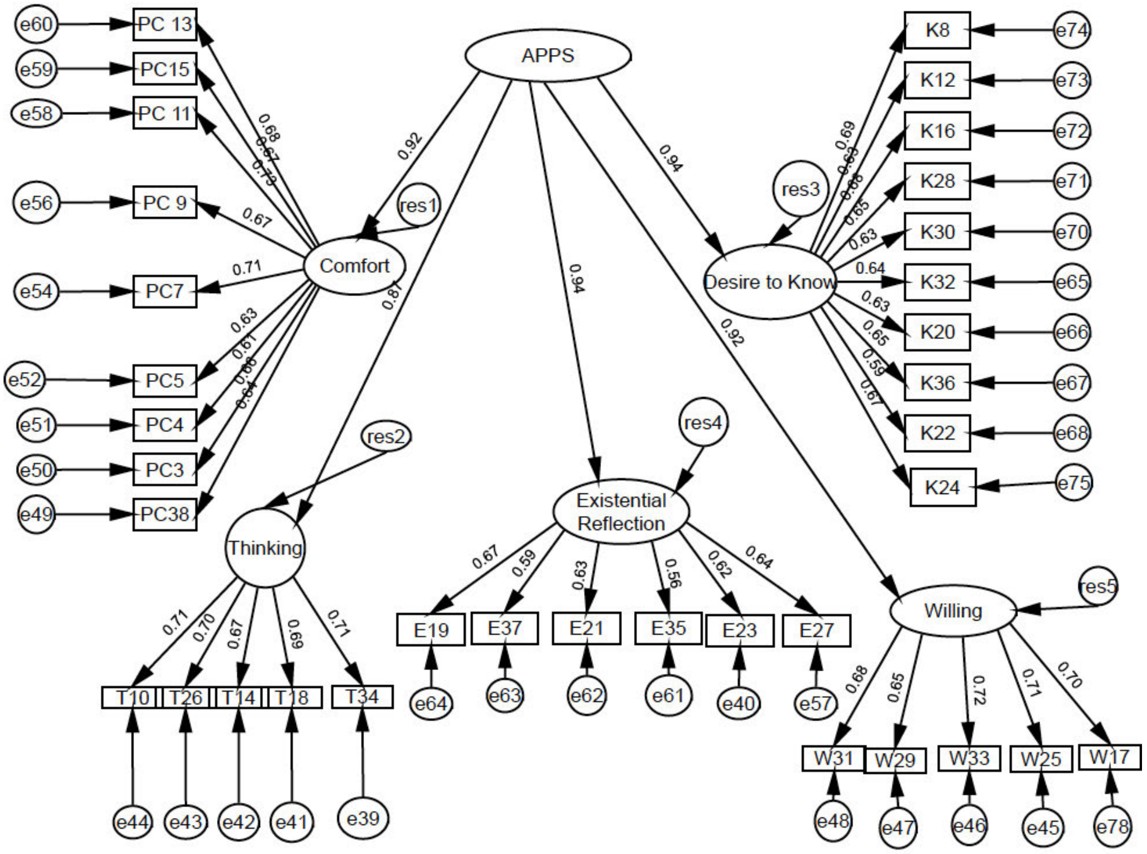


Figure 5 *:CFA Model of APPS (35) Based on EFA with PCA*

Model estimation

The parameters were estimated using maximum likelihood method. Results from the EFA model evaluation yielded factor loadings (the standardized weights) shown in Figure 5. Standardized weights were reasonably more robust than the theoretical model, ranging from .62 to .72. All regression weights are statistically significant at 0.05 level and no S.E values were less than .07 or greater than .09.

Model evaluation

The model was evaluated based on several priorly mentioned fit indices. The model fit indexes are presented in Table 21. The chi-square test for the EFA model was statistically significant χ^2 (555) = 1268.0, p<.000, indicating that the model's covariance structure was significantly different from the observed covariance matrix. Due to the large sample size this was expected. The χ^2/df ratio is 2.28 indicating a good fit. The model fit indices were also improved NFI = .862, IFI = .918, TLI =.911, CFI =.917, and RMSEA =.049, which showed the model had adequate fit.

Additional modifications were investigated to ascertain whether an improved fit was possible. Covariances that led to a positive change in the model with modification indices greater than 10 were evaluated. Again, only the psychological comfort scale item# 3 and #7 remained related. The single modification index of 22.622 with a par change of .095 was appreciated and the single covariances was applied. Chi square remained significant (X^2(554) =1244.43; p=.000). Standardized regression weights were improved (Figure 6).

Item # 4 in the psychological comfort scale “I feel at ease to discuss the pros and cons of life sustaining treatment at end of life” and Item # 8 “I prefer to make an advanced directive when I am healthy” in the Desire to Know scale in this model had a modest correlation between measurement errors in the two different factors (M.I. 17.233 par change .157). When the items #4 and #8 were placed in psychological comfort together, modifications indices worsened. However, when placed in the desire to know fit indices were essentially the same as the final modified model (Figure 7). Removal of Item #4 was intrusive to the model and revealed no benefit to regression weights X^{2}(521) =1140.18; p=.000); X^2/df=2.19 (Figure 8). Future study will be necessary in diverse populations to evaluate the relationship of items # 4 and #8.

The results from modified second order CFA APPS (35) model evaluation yielded pattern coefficients relating the factors with the items as robust as the unmodified EFA 5-factor model; ranging from .59 to .73. Fit indexes for this model revealed a persistent statistically significant chi square test showed values that when combined indicated an adequate fit (Table 21).

Table 21

Model Fit of Five-Factor Second Order CFA Structure with and without Re-specification

Model					Fit Indices					AIC	BIC
	$X^2(p=.000)$										
	Value	*df*	X^2/df	*RMSEA*	*NFI*	*CFI*	*IFI*	TLI	PNFI		
APPS (35)	1268.0	555	2.28	.049	.862	.917	.918	.911	.804	1418.0	1740.3
Modified APPS (35)	1244.4	554	2.25	.048	.865	.920	.920	.914	.805	1396.43	1723.0 .

Note. RMSEA= root mean square error of approximation NFI= Normed Fit Index. CFI =Comparative Fit Index, IFI=Incremental Fit Index, TLI= Tucker Lewis Index, PNFI=Parsimony-Adjusted Measures Index

Model comparison

Model comparison indexes were computed to compare the theoretical and EFA five-factor models. Both the Akaike Information Criterion (AIC) and Browne-Cudeck Criterion (BCC) were lowest for the second order modified structure, indicating that the EFA modified second order structure provides the best fit for the data (Table 22).

Table 22

Model Fit Comparison

CFA Model	***AIC***	***BCC***	***X2/df <3***	***ΔAIC***	***Δ BCC***
Theoretical 5-factor model	1646.2	1657.7	2.69	-	-
CFA 5 factor Model	1418.0	1428.7	2.28	-228.2	-229
Modified CFA 5 factor Model	1396.43	1407.2	2.25	-249.6	-250.7

Note: AIC= Akaike Information Criterion; BCC = Browne-Cudeck Criterion

Model re-specification

The results of the comparison of the models identified the modified five-factor model based on CFA PCA with Promax rotation as the better model. Both AIC and BCC are improved, and all indices of fit are better in the modified CFA model. As the model had more than 400 samples the chi square as expected was significant. The chi square goodness of fit *X2*/df=2.25 is below the desired 3 value. Prior literature suggested less than 2, however conventional literature supports a range below 3 (Meyers et al., 2021). Other indices in comparison to the other models support a good fit. The model modifications suggest interdependence among the items in the theoretical model. There is less interdependence in the CFA model with items #3 and #7 interdependent in the psychological comfort scale.

Thus, future study should reexamine CFA as the current community sample may not be generalizable to other populations. The respecified model with its standardized coefficients is presented below in Figure 6. As aforementioned, fit and all the pattern coefficients were reasonably robust. These results suggest that the proposed five-factor structure of the APPS was supported using the data from this independent sample. Less interdependence between unobserved errors exists in the final model. Removal of items # 2 and # 6, due to poor factor loadings improved fit. Pairs of items #3 and #7 as well as items #4 and #8 have correlations in this independent sample. Future study should look at the performance of the items and wording of all the variables.

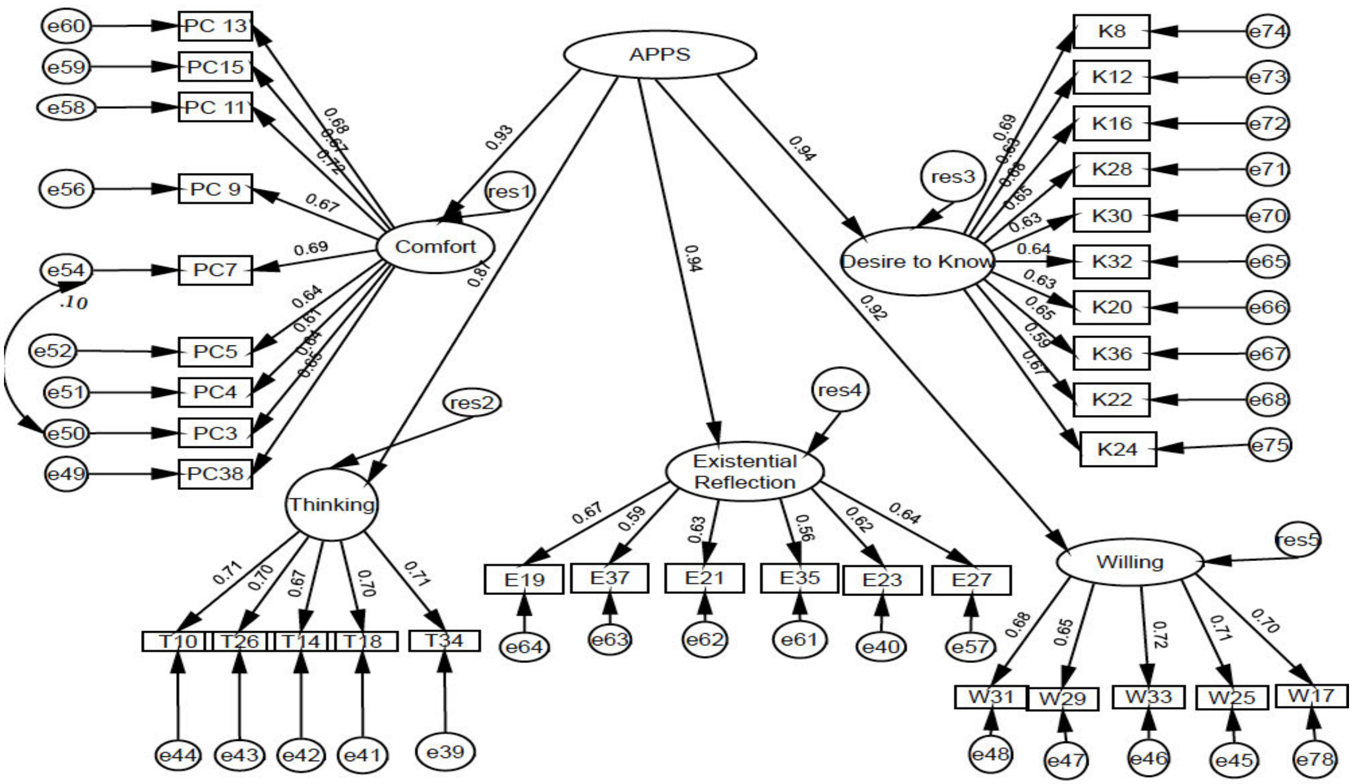


Figure 6: *Final Five Factor CFA Modified Model for APPS 35 item*

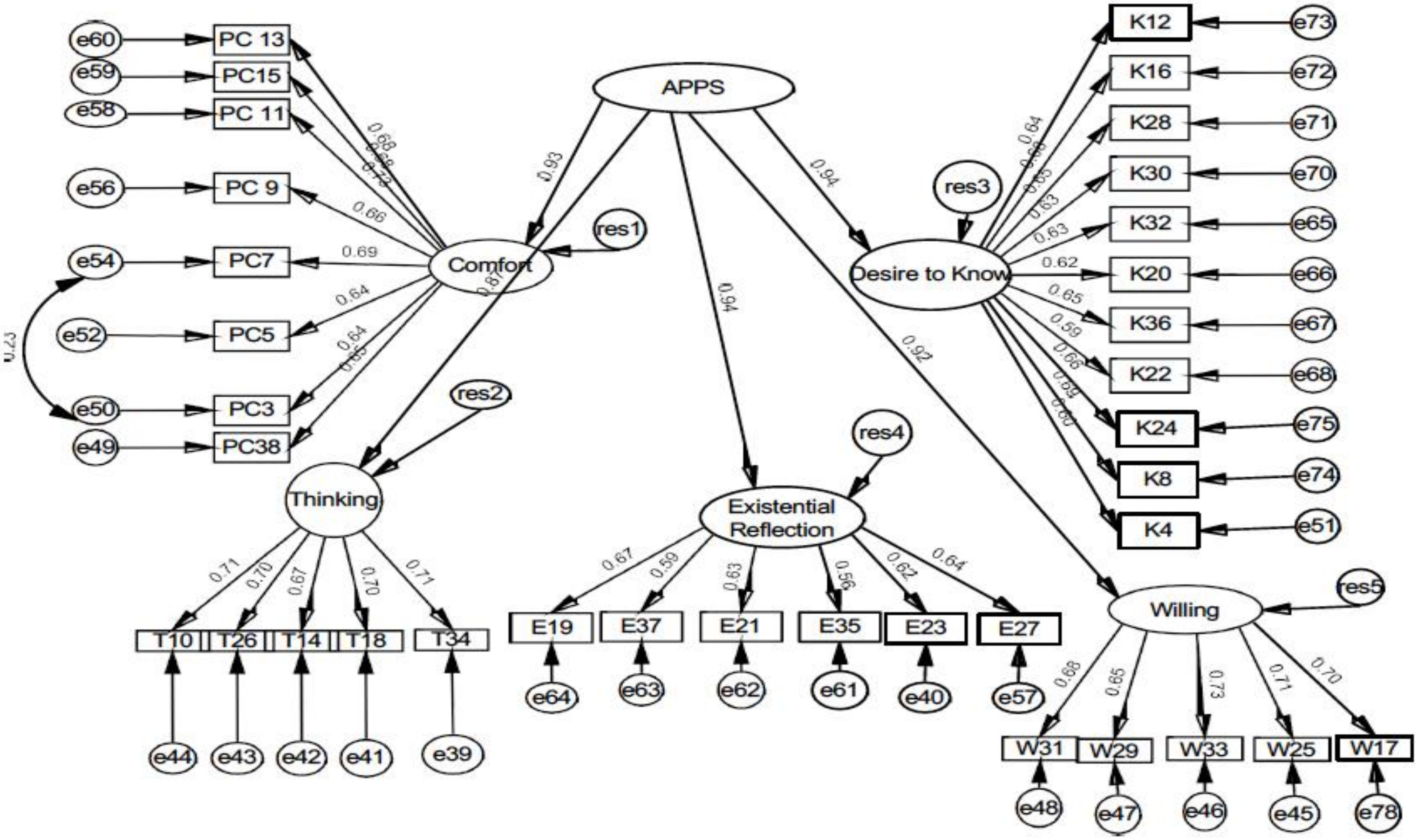


Figure 7: *Alternative Final Factor Modified Model: APPS -35*

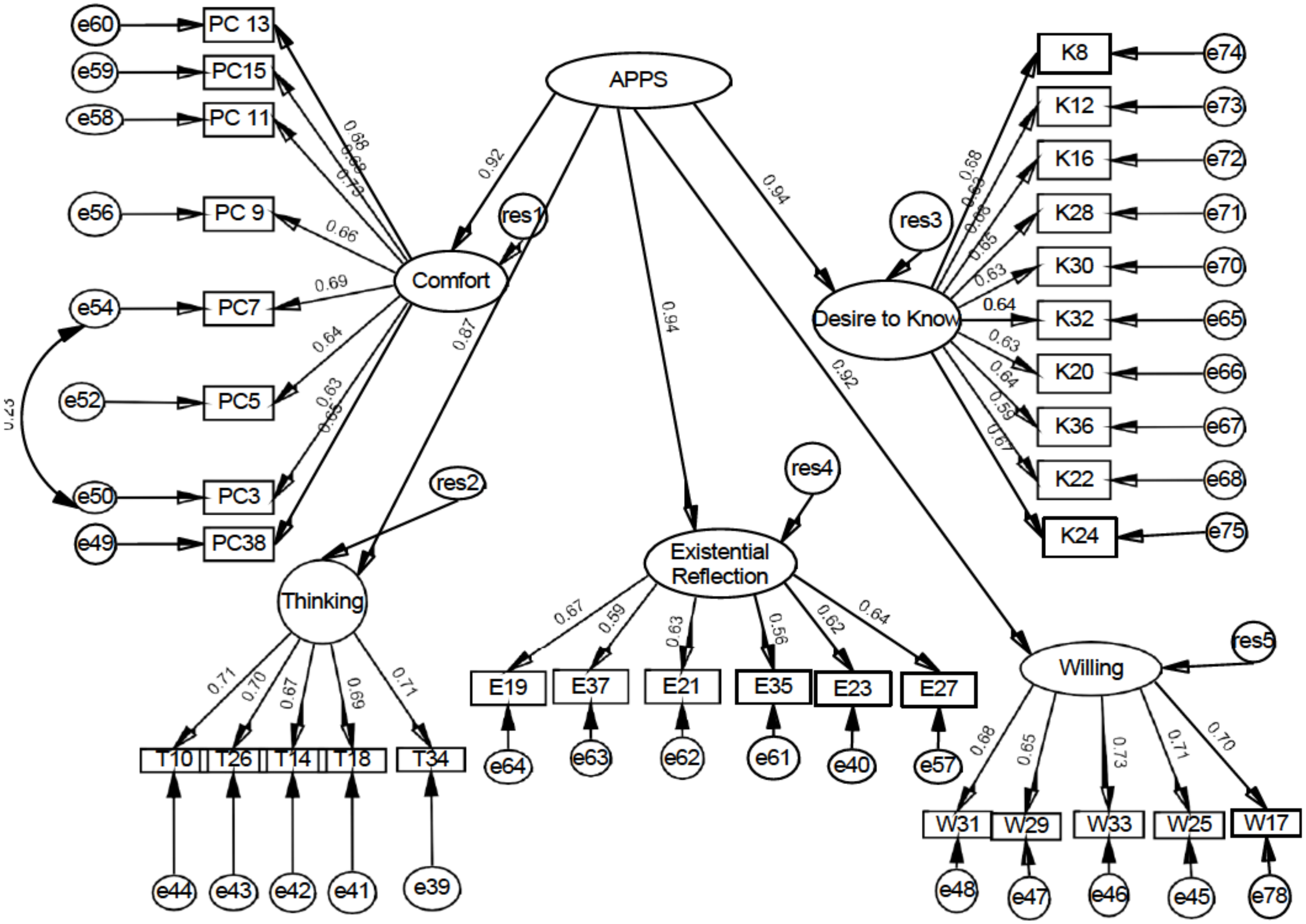


Figure 8: *Alternative Final Factor Modified Model: APPS -34*

Summary of Confirmatory Factor Analysis

The intent of this research was to develop the APPS to measure the phenomenon of psychological readiness for ACP. A theoretical set of 38 items evaluated on a 5-point summative response scale of strongly disagree to strongly agree were subjected to a principal component analysis (PCA) with a ProMax rotation. From that analysis, 37 items emerged as viable indicators of shifting representing 5 underlying factors. Further appreciation of factor loadings reduced the APPS scale to 35 items with preserved reliability.

The present study reported the results of a confirmatory factor analysis to evaluate that hypothesized factor structure based on the data from an independent sample of 543 participants in community settings. The initial 5-factor theoretical model proposed in the confirmatory analysis, shown in Figure 3, was evaluated without including any correlations between error variables. The interdependence of the items is an acknowledged limitation of the model, indicating redundancy because the observed errors are frequently correlated. However, error correlations are difficult to determine at the outset of model creation (Meyers et al., 2021). The model will require continued future study in diverse populations to improve the model.

An examination of the modification indexes suggested that the addition of some correlations between pairs of errors would improve model fit. In both modified models, all proposed factors had associations and correlations between errors. Upon review of the items, particularly in thinking, existential reflection and psychological comfort have shared meaning and wording. This suggests that the factors have a little more in common with each other beyond a shared factor variance. The modified model based on CFA accounted for these correlations as it seemed reasonable to take the correlations into account in specifying the 5-factor model.

The model based on the EFA had the best fit. The removal of item # 2 and #6 reduced correlations in each scale. The theoretical factor of psychological comfort was improved by the removal of items that related to feeling at ease when discussing or planning end of life. The proposed factor Psychological Comfort remained with only one error pair; e50 (associated with Item #3 comfort talking about EOL care) and e54 (associated with Item# 7 feeling prepared making decisions about EOL ahead of time). Willingness and desire to know had interdependence. The variables have shared meaning and wording that may give them a commonality with each other beyond their shared factor variance, and thus it seemed reasonable to take these correlations into account in specifying the model.

The respecified EFA model with its standardized coefficients is presented in Figure 4. The respecified model had only one correlation between pairs of error and thus was chosen as the represented model. The results suggest that the proposed EFA five-factor structure of the APPS was supported using the data from this independent sample.

Construct Validity Through Hypothesis Testing

This section will evaluate hypotheses a-d as follows:

(a) There is a moderate. negative relationship (correlation coefficient $r < -.5$) between APPS scores and the 23-item Mishel Uncertainty in Illness Scale (MUIS-C) scores.

(b) The APPS scores have strong correlations (correlation coefficient $r > .7$) with the existing Advance Care planning Readiness Instrument (ACPRI)

(c) The APPS scores will demonstrate moderate correlation (correlation coefficient r

between .5 and .7) with the Struggle with Illness and the Peaceful Acceptance subscales of the PEACE questionnaire

(d) The APPS scores will demonstrate moderate correlation (correlation coefficient r between - .5 and – .7) with the short health anxiety inventory (SHAI)

Through Pearson correlation statistics, APPS subscale and the total scores were correlated with MUIS-C, ACPRI, PEACE subscales and SHAI to test hypotheses a to d. Table 23 presents the correlations using the original theoretical model and in Table 24, the 5 factors are based on the final CFA constructs as shown in Figure 6. These results show hypotheses b & c were supported whereas hypotheses a & d were not supported. Some p values are less than .05 because of the large sample size in this study, even though the APPS and its subscales had weak relationships with MUIS_C and SHAI (Table 23 and 24).

Table 23

Pearson's Correlations of the Theoretical APPS and Subscales

Scale	Theoretical APPS Mean	Psychological Comfort	Desire to Know	Thinking	Willingness	Existential Reflection
MUIS_C	.09*	.07	.09*	.11*	.07	.16**
ACPRI	.69**	.62**	.71**	.69**	.62**	.66**
PEACE	.52**	.47**	.53**	.55**	.50**	.55**
StrgIllness	.42**	.37**	.44**	.46**	.38**	.48**
Acceptance	.50**	.47**	.49**	.50**	.51**	.46**
SHAI	.04	.02	.06	.07	.03	.07

Note: [1] StrgIllness = Struggle with Illness

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

Table 24

Scales Correlations with Revised APPS and Subscales

Scale	Revised APPS	Psychological Comfort	Desire to Know	Thinking	Willingness	Existential Reflection

MUIS_C	.10*	.10*	.09*	.11*	.06	.01*
ACPRI	.73**	.65**	.67**	.64**	.64**	.64**
PEACE	.57**	.50**	.52**	.50**	.51**	.49**
StrgIllness[1]	.47**	.40**	.43**	.43**	.39**	.44**
Acceptance	.53**	.49**	.47**	.45**	.52**	.41**
SHAI	.06	.03	.01	.05	.09*	.09*

Note: [1] StrgIllness = Struggle with Illness

**. Correlation is significant at the .01 level (2-tailed).

*. Correlation is significant at the .05 level (2-tailed).

An interesting finding is the relatively weak but positive correlation coefficients between MUIS_C and APPS indicating higher uncertainty is associated with higher preparedness. Although APPS was not strongly correlated with uncertainty as measured by MUIS-C, negative correlations existed with sociodemographic measures of uncertainty. Prognostic awareness was measured by asking participants their understanding of their mortality. When uncertainty as measured by MUIS_C was controlled for, APPS and prognostic awareness were weakly negatively correlated (Pearson's r= -.107, p=.013). This relationship remained. Pearson's correlations for prognostic awareness were also weakly negatively correlated with APPS (Pearson's r= -.108, p=.012), psychological comfort (Pearson's r= -.10, p=.017), desire to know (Pearson's r= -.10, p=.018), thinking (Pearson's r= -.13, p=.002) and existential reflection (Pearson's r=-.11, p=.010). Participants who reported being uncertain with their life expectancy, were also significantly negatively correlated with APPS (Pearson's r= -.10, p=.02).

APPS scores demonstrated a moderate correlation (correlation coefficient r between .5 and .7) with PEACE and Acceptance subscale. Contrary to the hypothesis, the APPS scores did not demonstrate any significant correlations with SHAI.

Criterion Validity

In this study, the gold standard for APPS is defined as preparedness for the completion of an AD, living will, health care proxy, or MOLST. It is hypothesized that the APPS scores can significantly predict the psychological intent to complete an AD or the completion of at least one ACP behavioral outcome.

Logistic regression modeling was conducted to identify APPS ability to predict the completion of an AD as a gold standard after controlling for covariates such as uncertainty, acceptance, EOL communication, etc. To identify covariates Pearson correlations were utilized with the results displayed in Table 25.

Table 25

Correlations among Dependent and Independent Variables of Having AD

Variable	M (SD) /n (%)	1$^{a:}$	2$^{a:}$	3^{a}	4	5	6	7	8
1. Have AD	267 (49)	-							
2. MOLST	280 (52)	.22**							
3. Living Will	331 (61)	.17**	.40**	-					
4. Uncertainty	73.3 (12.4)	.16**	.12**	.03	-				
5. Acceptance	3.04 (0.5)	.15**	.13**	.10*	-.04	-			
6. Anxiety	4.7 (1.1)	*.05*	*.14***	*.12***	.19**	*-.09**	-		
7. Preparedness	3.9 (0.6)	*.19***	*.14***	*.12***	*.10**	*.53***	*.06*	-	
8. EOL Comm	*344 (63)*	*.26***	*.37***	*.42***	*.08*	*.08*	*.12***	*.19***	-
9. Past AD Exp.	*485 (89)*	*.28***	*.17***	*.18***	*.07*	*.15***	*.14***	*.23***	*.20***

Note: $^{a:}$ Spearman correlations. The rest are Pearson Correlations.

The predicting variables in this study were routine discussion about ADs, Past ACP experiences, preparedness (APPS), uncertainty (MIUS_C), EOL communication and acceptance (Peaceful acceptance subscale). Social desirability was controlled for in the model as it was also correlated with having an AD (r= -.22; p<.001). Communication was differentiated between routine discussion and EOL communication. The variance inflation factor (VIF) was 1.20 between the two types of communication indicating that multicollinearity was not evident. Results of the logistic analysis omnibus test indicated that the seven-predictor model provided a statistically significant prediction of advanced directive completion, χ^2 (8, 427) = 77.49, p < .001. The Hosmer and Lemeshow Test were nonsignificant $\chi^{2\,(}$8, 427) =12.04, p=.15 indicating that the prediction model fit data well.

Table 26 presents the regression coefficients, the Wald test, the odds ratio [Exp(B)], and the 95% confidence intervals (CI) for odds ratios for each predictor. The Wald test indicated that both experiences with ACP, AD discussion with a provider, social desirability and EOL communication were statistically significant predictors of having an AD. The influence of having experiences with ACP/ADs with loved ones were strong; participants were approximately 3.6 times (CI = 1.37, 9.98) more likely to have an AD, adjusting for social desirability. For each likelihood of having an AD, there was a nonsignificant 1.12 times increase in preparedness scores. EOL communication also demonstrated a two-time greater likelihood of having an AD.

Table 26

Results of the Multiple Regression Analysis Using Having AD as the Criterion

	B	S.E.	Wald	p	OR [95% CI]
Experiences ACP/AD	1.31	0.51	6.65	0.01	3.70 [1.37, 9.98]
AD Discussion	0.61	0.25	6.19	0.01	1.84 [1.14, 2.98]
Acceptance	0.20	0.26	0.58	0.45	1.22 [0.73, 2.04]
Uncertainty	0.27	0.01	0.33	0.57	1.01 [.99, 1.03]
Preparedness	0.12	0.26	0.20	0.65	1.12 [0.68,1.86]
EOL Communication	0.71	0.24	8.15	.005	2.04 [1.24, 3.35]
Social Desirability	-0.41	0.20.	4.18	.041	0.66 [0.45, 0.98]

Note: Model Summary -2 Log likelihood 490.0; Nagelkerke R^2=0.22

Classification success for the sample was high, with an overall prediction success rate of 68% (n=427), correct prediction rates of 84% (n=214) for successful advanced directive completion and 45%(n=77) for those who do not have ADs. This classification cutoff corresponded to an accuracy better than chance with a good positive likelihood. Specificity of the model to rule in having an AD was not demonstrative in this study. However, sensitivity to rule out having an AD was demonstrated. Table 27 below demonstrates the ability of the regression model to predict having an AD.

Table 27

Predictive Values of Having an AD Using the Theoretical Model

Statistic	**Value**	**95% CI**
Sensitivity	84.3%	79.2% to 88.5%
Specificity	44.5%	37.0% to 52.2%
Positive Likelihood Ratio	1.52	1.32 to 1.75
Negative Likelihood Ratio	0.35	0.25 to 0.49
Positive Predictive Value	69.0%	63.6% to 74.1%
Negative Predictive Value	65.8%	56.5% to 74.3%
Accuracy	68.2%	63.5% to 72.5%

In summary, the regression models suggest the theoretical model can better predict who will not have an AD, but is less likely to predict those with an AD.

Generalized linear modeling was conducted to investigate the study's theoretical model of preparedness as a predictor of AD completion. The model included preparedness, acceptance, anxiety, and social desirability fitted as intercepts was fitted against having completed an advanced directive. Additional factors correlated to having an AD included employment status, religion affecting EOL, experiences with AD/ACP, death of a loved one, AD discussion, EOL communication and understanding of one's mortality.

Strong associations were noted between having ADs and preparedness as well as those with health anxiety while all other variables had weak associations. Table 28 displays Phi and Cramer's V statistics for dichotomous and nominal variables, respectfully.

Table 28

Coefficients Measuring Associations of Variables with Having an AD

Variable	n (%)	1[a:]	2[b]
1. AD Discuss[1]	260 (48)	.25**	
2. EOL Com[2]	262 (49)	.26**	
3. Experience with AD/ACP	267 (50)		.23**
4. Religion effecting EOL	169 (31)		.14*
5. Employed	267 (50)		.12*
6. Uncertain of Mortality	266 (50)	*	.17**
7. Death of Loved One	164 (30)	*.28***	
8. Anxiety	310 (57)		.54*
9. Acceptance	267 *(50)*		.27*
10. APPS	310 (57)		.53*
11. SDRS[3]	266 (50)		.28**

Note: [a:] Phi correlations.
[b] Cramer's V correlation
[1] AD Discuss= Routine AD Discussion
[2] EOL com = EOL communication
[3]SDRS=Social Desirability

*p <.05 ** p<.001

Variables with correlations greater than .25 were entered into the model. A sample of 425 participants (78%) entered the model yielded a statistically significant model X^{2} (7) maximum likelihood ratio=59.84, p<.001. EOL communication and routine AD discussion demonstrated significant model effects of having and AD; with near significant model effects demonstrated by preparedness and acceptance (Table 29).

Table 29

Results of Generalized Linear Modeling with Having AD as Criterion

	B	SE	Wald	p	Exp(B) [95% CI]
EOL Communication	0.74	.22	10.81	.001	2.09 [1.35, 3.23]
APPS	0.15	.08	3.44	.06	1.16 [0.99, 1.35]
Acceptance	0.16	.09	3.33	.07	1.17 [0.99, 1.38]
Anxiety	0.03	.04	0.61	.43	1.03 [0.95, 1.11]
Death of Loved One 2Yrs	0.04	.21	0.04	.92	0.99 [0.84, 1.16]
AD Discussion with HCP	0.71	.22	9.95	.002	2.03 [1.31, 3.14]
Social Desirability	0.41.	.18	5.19	.02	1.51 [1.06, 2.15]

Dependent variable: Have an AD
Model: Death of a loved one in 2 yrs, AD Discussion with HCP, Anxiety, Acceptance, Preparedness, EOL Communication, social desirability

The gold standard use of the scale is to also predict intent to complete ADs; thus, intent to complete an AD as the dependent variable was also tested by a logistic regression model was used to analyze. Factors have significant relationships with intention to complete ADs in 30 days are presented in Table 30.

Table 30

Factors Correlates with Intent to Complete AD in 30 days

	M (SD) /n (%)	1[a]	2[a]	3[a]	4	5	6	7	8	9
1. AD-30Day[1]	121 (77)									
2. MOLST	280 (52)	$.36^{**}$	-							
3. Living Will	331 (61)	$.32^{**}$	$.40^{**}$	-						
4.AD Discuss[2]	153 (28.2)	$.41^{**}$	$.32^{**}$	$.37^{**}$						
5. Uncertainty	73.3 (12.4)	$.20^{*}$	$.12^{**}$	0.03	$.13^{**}$	-				
6. SHAI	4.67 (1.05)	.09	$.14^{**}$	$.12^{**}$	$.16^{**}$	$.19^{**}$	-			
7. Acceptance	3.04 (0.51)	$.20^{*}$	$.13^{**}$	$.10^{*}$	$.09^{*}$	-.04	$-.09^{*}$	-		
8. APPS	3.92 (0.56)	$.21^{**}$	$.14^{**}$	$.12^{**}$	$.13^{**}$	$.10^{*}$	.06	$.53^{**}$	-	
9. EOLCom[3]	344 (63)	$.25^{*}$	$.37^{**}$	$.43^{**}$	$.39^{**}$	.08	$.12^{**}$	.08	$.19^{**}$	-

Note: [1] AD-30Day = Intention to complete AD in 30 days with two categories: Very likely or likely and not likely at all.
[2] AD Discuss= Routine AD Discussion
[3] EOL com = EOL communication
[a]: Spearman correlations. The rest are Pearson Correlations.
$^{*}p<0.05$ $^{**}p<.001$

In multiple regression analysis, preparedness, uncertainty, acceptance, routine AD discussion, social desirability and EOL communication was included in the model to predict intent to complete ADs in 30 days, X^2 (6, 147) =47.20, p<.001. Table 31 below displays the coefficients, Wald test, Exp (B) and confidence intervals for intent to complete AD in 30 days. Overall, preparedness, uncertainty and having an AD discussion with a provider were significant predictors of intent to complete an AD in 30 days.

Table 31

Results of the Multiple Regression Analysis (using Yes Very Likely Intent to Complete AD in 30 Days as the Criterion)

Variable	**B**	**SE**	**Wald**	**p**	**OR [95% CI]**
AD Discussion	-2.50	.72	12.06	<.001	0.08 [0.02, 0.34]
Preparedness	1.41	.63	4.98	.03	4.08 [1.19, 14.04]
Uncertainty	1.47	.62	5.67	.02	4.37 [1.30, 14.70]

Model Summary -2 log likelihood 222.27, Nagelkerke R Square .33
Note. B = estimated unstandardized regression coefficient, SE = standard error, % CI = confidence interval; 1df= degree of freedom.

People without an AD discussion are 86.4% less likely to have an intention to complete AD in 30 days compared to those having had such a conversation. The model predicted intent to be very likely to complete an AD in 30 days, 87% of the time. Preparedness and uncertainty predicted the criterion of intent to complete an AD. Intent to complete an AD and use of APPS in clinicians with hesitancy to have AD discussions is a promising area of future research to analyze participants prospectively in experimental interventional studies for actual completion rates.

Hypothesis 1. The Advance Planning Preparedness Scale will have better criterion validity than the ACPRI.

In this full study, participants were surveyed regarding their possession of an AD, health care proxy, living will, MOLST as well as their intent to have an AD in 30 days and 6 months. Bivariate analysis was conducted to see the relationship between APPS and ACPRI and the criterion of having any AD or intent to have an AD. Both scales behaved similarly correlations with intent to complete an AD in 30 days, completion of a living will and the presence of either living wills or MOLSTs (Table 32). In regards to intent to complete an AD in 6 months, ACPRI was not correlated while APPS was significantly correlated.

Table 32

Factors Correlate with Any AD

	APPS	ACPRI
Have an AD	.18**	.22**
AD intent 30 days	.24**	.27**
AD intent 6 months	.19*	.01
Have a health care proxy	.18**	.13**
Have a MOLSTs	.13**	.17**
Completed a living will	.12**	.10*
Either living wills or MOLSTs	.14**	.13**
Have any of the ADs	.13**	.19**

*p<.05 **p<.01

The correlations between ADs and both scales were low ranging from with Pearson correlations ranging from .10 to .27. ACPRI demonstrated predictability when entered into a regression model with a variable that represented either completing a health care proxy, advanced directive, MOLST or living will (Table 33 & Table 34). The ACPRI predicted having an AD correctly 66.7% of the time compared to 66.2% of the time by APPS (Table 35). Both scales behaved similarly.

Table 33

ACPRI to Predict Any ADs (HCP, AD, MOLST or Living Will) as Criterion[1]

						95% C.I.for EXP(B)	
	B	S.E.	Wald	Sig.	Exp(B)	Lower	Upper
ExpACP[2]	0.72	0.21	11.89	<.001	2.05	[1.36, 3.08]	
Acceptance	0.01	0.22	0.00	0.97	1.01	[0.65, 1.56]	
Anxiety	-0.01	0.09	0.02	0.89	0.99	[0.82, 1.19]	
Uncertainty	0.32	0.18	3.07	0.08	1.38	[0.96, 1.96]	
EOL Comm	0.63	0.20	10.13	0.00	1.87	[1.27, 2.76]	
ACPRI	0.52	0.22	5.69	0.02	1.69	[1.1, 2.59]	

Note: [1] Variables entered in the model: ACPRI. Experiences ACP/AD, AD Discussion, Acceptance, Health Anxiety, Uncertainty, EOL Communication

[2] ExpACP = Experiences in ACP or AD.

Table 34

APPS to Predict Any ADs (HCP, AD, MOLST or Living Will) as Criterion

						95% C.I.for EXP(B)	
	B	S.E.	Wald	Sig.	Exp(B)	Lower	Upper
Exp AD	0.72	0.21	12.06	<.001	2.06	[1.37,	3.09]
Acceptance	0.192	0.22	0.76	0.38	1.21	[0.79,	1.86]
Anxiety	-0.01	0.09	0.00	0.95	0.99	[0.83,	1.19]
Uncertainty	0.37	0.18	4.21	.040	1.44	[1.02,	2.05]
EOL Comm	0.67	0.20	11.62	<.001	1.95	[1.33,	2.87]
APPS	0.16	0.21	.62	0.43	1.18	[0.78,	1.76]

Model Summary -2 log likelihood 124.02, Nagelkerke R Square .14

Table 35

Diagnostic Accuracy Indicators: ACPRI vs. APPS to Predict Any ADs

Scale	ACPRI	APPS.
Sensitivity (95% CI)	88.9%. [84.9, 92.1].	88.1%. [84.1,91.4].
Specificity	29.1%. [23.3,36.2].	27.9. [21.9, 34.6].
PLR[1] (95% CI)	1.26. [1.1, 1.4].	1.22. [1.1, 1.3].
NLR[2] (95% CI)	0.38 [.26, .55].	0.43 [.30, .62].
PPV[3] [95% CI]	66.7%. [62.0, 71.1].	66.2%. [61.6, 70.4].
NPV[4] [95% CI]	62.50% [52.0, 72.0].	59.4%. [48.9, 69.3].
Accuracy [95% CI]	65.90% [61.6, 69.9]	65.50% [60.8, 69.0]

Note: [1] PLR = Positive Likelihood Ratio

[2] NLR = Negative Likelihood Ratio

[3] PPV = Positive predictive value

[4] NPV = Negative predictive value.

Since EOL discussion is a component of ACP, self-reported EOL discussion was used as another criterion for psychological preparedness. Separate logistic regression was performed for APPS and ACPRI as a predictor for EOL discussion. Experiences with ACP/AD, having an AD discussion, acceptance, health anxiety and uncertainty were entered in the logistic regression model as covariates. Table 36 and Table 37 presents the logistic regression results.

Table 36

ACPRI Predicting End of Life Communication as Criterion[1]

						95% C.I.for EXP(B)	
	B	S.E.	Wald	Sig.	Exp(B)	Lower	Upper
Exp AD[2]	0.53	0.21	6.47	0.01	1.70	[1.13	,2.56]
Acceptance	-0.20	0.24	0.65	0.42	0.82	[0.51	,1.32]
Anxiety	0.16	0.10	2.29	0.13	1.17	[0.96	,1.43]
Uncertainty	-0.03	0.20	0.02	0.90	0.98	[0.66	,1.44]
AD Discuss	0.54	0.22	5.81	0.02	1.71	[1.11	,2.66]
ACPRI	1.62	0.21	58.50	<.001	5.04	[3.33	,7.62]

Note: [1] Variables entered in the model: ACPRI, Experiences ACP/AD, AD Discussion, Acceptance, Health Anxiety, Uncertainty, EOL Communication

[2] ExpAD = Experiences in ACP or AD.

Model Summary -2 log likelihood=508.25, Nagelkerke R Square .25

Note: model cases selected for social desirability

Table 37

APPS Predicting End of Life Communication as Criterion[1]

						95% C.I.for EXP(B)	
	B	S.E.	Wald	Sig.	Exp(B)	Lower	Upper
Exp AD[2]	0.57	0.21	7.42	0.01	1.77	[1.17	2.67]
Acceptance	-0.24	0.24	0.99	0.32	0.78	[0.49	1.26]
Anxiety	0.16	0.10	2.38	0.12	1.17	[0.96	1.43]
Uncertainty	-0.06	0.20	0.08	0.78	0.94	[0.63	1.40]
AD Discuss	1.61	0.21	57.89	<.001	5.01	[3.31	7.58]
APPS	0.65	0.24	7.56	0.01	1.92	[1.21	3.05]

Note: [1] Variables entered in the model: APPS, Experiences ACP/AD, AD Discussion, Acceptance, Health Anxiety, Uncertainty, EOL Communication

[2] ExpAD = Experiences in ACP or AD.

Model Summary -2 log likelihood=510.23, Nagelkerke R Square .24

Note: model cases selected for social desirability

In both models, the EOL criterion was predicted similarly. Prior experiences with ACP/AD, routine AD discussion and both scales were predictive of EOL communication. In terms of statistics for sensitivity and predictive value APPS performed similarly to ACPRI with regard to specificity for EOL discussion. There was no statistical difference between the diagnostic evaluation of both tests. The model summaries for both scales revealed -2 log likelihood summaries and Nagelkerke R^2 scores that were similar. At the cut off value of 0.5 both scales had an overall correct percentage of 72-73% when observing EOL discussion in this population (Table 38).

Table 38

Diagnostic Accuracy Indicators: ACPRI vs. APPS to Predict EOL Discussion

Scale	ACPRI	APPS
Sensitivity (95% CI)	76.6%. [71.9, 80.9].	76.2%. [71.4, 80.6].
Specificity	65.0%. [57.1,72.4].	63.6% [55.7, 71.0].
PLR[1] (95% CI)	2.19. [1.8, 2.7].	2.09. [1.7, 2.6].
NLR[2] (95% CI)	0.36 [0.29,.45].	0.37 [0.30, 0.47].
PPV[3] [95% CI]	82.9%. [78.4,86.8].	82.0%. [77.4, 86.0].
NPV[4] [95% CI]	55.60% [48.2, 62.9].	55.1%. [47.7, 62.3].
Accuracy [95% CI]	73.00% [69.0, 76.8]	72.20% [68.2, 76.1]

In sum, in this Western sample, APPS was a significant variable in predicting EOL communication but not for predicting the presence of any advanced directive (HCP, MOLST or Living Will). APPS performed similarly to ACPRI in predicting positive likelihood of EOL communication and presence of an AD.

Research Question #1 To what extent does APPS correlate with social desirability as measured by the Shortened Marlowe-Crowne Social Desirability Scale (MCSDS)?

Research question #1 was answered first to understand whether further analysis would need to be controlled for social desirability. As the data was normally distributed, Pearson correlation was used. The APPS has a moderate negative relationship with social desirability as measured by the Shortened Marlowe-Crowne Social Desirability Scale (MCSDS), r (2) = -.516, p <.001

Hypothesis 2. The correlation of social desirability with APPS is significantly lower than that with ACPRI.

To test hypothesis 2, Lee & Preacher's (2013) online asymptotic z-test based on Setiger's Equations (1980) were used to compare the correlation coefficients. Table 39 demonstrates hypothesis 2 was supported by the data. This suggests the need to select cases for social desirability in other analysis.

Table 39

Z Test for the Difference in Correlation Coefficients

	Correlation Coefficient			
	SD^1	ACPRI	*z statistics (N)*	*p*
APPS	-.516**	.732**	2.27 (543)	.012^a
ACPRI	-.574**			.023

Note: ^{1} SD = Social Desirability

** Correlation is significant at the 0.01 level.

$^{a.}$ One-tailed test.

^{b} Two-tailed test

Research Question #2

Research question #2 asks; “What characteristics of patients are correlated with the preparedness for ACP and subscales of the newly developed Advance Planning Preparedness Scale (APPS)?”

For demographic variables with 3 or more categories, Spearman correlation was used and for dichotomous demographic variables, Pearson correlations was used to identify relationships with APPS and its subscales. Table 40 presents these correlation coefficients which ranged from .003 to .26, indicating very weak to weak relationships.

Table 40

Demographic Factor Correlates with APPS and Subscales

	APPS35	Comfort[1]	Know[2]	Thinking	Willing	ExistR[3]
APPS35	-	.91**	.91**	.85**	.85**	.86**
AD Exp. [4]	.18**	.21**	.12**	.21**	.15**	.12**
Employed	.11*	.13**	.07	.08	.07	.10*
Hispanic	-.09*	-.08	-.12**	-.12**	-.003	-.07
HCP[5]	.10*	.14**	.11**	.11**	-.005	.07
SS-EOL [6]	.10*	.09*	.10*	.10*	.10*	.05
KnowAD[7]	.10*	.07	.10*	.09*	.10*	.07
HaveAD[8]	.19**	.20**	.15**	.19**	.14**	.15**
InfoADs[9]	.16**	.15**	.15**	.16**	.12**	.11**
AD-Discus[10]	.13**	.12**	.09*	.15**	.10*	.13**
AD30[11]	.21**	.23**	.14	.23**	.15	.22**
AD180[12]	.18*	.18*	.16*	.11	.14	.17*
KnowHP[13]	.18**	.20**	.14**	.17**	.14**	.15**
HaveHP[14]	.18**	.21**	.14**	.17**	.16**	.11*
KnowLW[15]	.14**	.09*	.16**	.13**	.12**	.10*
HaveLW[16]	.12**	.14**	.10*	.12**	.06	.08
EOLCOM[17]	.19**	.18**	.17**	.19**	.13**	.15**
WrittenEOL[18]	.12**	.14**	.10*	.13**	.09*	.07
VerbalEOL[19]	.14**	.14**	.14**	.13**	.10*	.07
KnMOLST[20]	.16**	.16**	.12**	.15**	.13**	.16**
HvMOLST[21]	.13**	.15**	.09*	.14**	.07	.11**
Mortality[22]	-.12**	-.12**	-.10*	-.13**	-.04	-.10*

ChrIllness[23]	.12*	.10*	.09*	.16**	.09*	.09*

Note: **Correlation is significant at the .01 level (2-tailed)
*Correlation is significant at the .05 level (2-tailed)
[1] Comfort = Psychological comfort
[2] Know = Desire to know
[3] ExistR = Existential Reflection
[4] AD Exp. = Having had an AD experience
[5] HCP = Being a health care provider
[6] EOL SS = Having social support at end of life
[7] KnowAD = Know what AD is.
[8] HaveAD = Having an AD
[9] InfoADs = Receive information about AD in the past
[10] CommHCP = Communicated with health care providers about AD
[11] AD30 = Intention to complete AD within 30 days.
[12] AD180 = Intention to complete AD within 180 days.
[13] KnowHP = Know what a health proxy is.
[14] HaveHP = Having a health proxy.
[15] KnowLW = Know what a living will is.
[16] HaveLW = Having a living will
[17] EOLCOM = Having had EOL communication with a healthcare provider.
[18] WrittenEOL = Having a written EOL plan
[19] VerbalEOL = Having a verbal EOL plan.
[20] KnMOLST = Know what MOLST or POLST is.
[21] HvMOLST = Having a MOLST or POLST.
[22] Mortality= Understanding One's Mortality
[23] ChrIllness=Have a Chronic Illness

Research Question #3. "To what extent does the components examined in the theoretical model predict preparedness?'

Factors in the theoretical model that have significant relationships with APPS were used to predict preparedness as measured by APPS. According to Table 40, the following demographic variables representing several intrapersonal factors had significant relationships with APPS; employment, social support, having an AD, past experiences with ADs, understanding one's mortality, intent to complete AD in 30 days, intent to complete AD in 180 days and having knowledge of ADs (e.g., living will, health care proxy and MOLST). As shown in Table 24 on p. 172, uncertainty, acceptance, struggling with illness, and EOL communication have significant relationship with APPS. Social desirability was also entered in the regression model to control for its influence on preparedness.

Stepwise linear regression analyses with 12 predictors were conducted to investigate whether preparedness is predicted by the components of the theoretical model. The regression model utilized the significant variables representing external factors, interpersonal factors, and death attitudes from the theoretical visual model of ACP depicted in Figure 1 on p.34. Assumptions such as minimal outliers, linear relationships, multivariate normality, multivariate homogeneity of variance and independence of errors were ensured. Multicollinearity was not an issue as tolerance was greater than .2 and VIF were not substantially greater than 5 (Meyers et al., 2021). No predictor factor reporting higher than a VIF of 2.39.

When social desirability was controlled for, the results of the regression indicated that acceptance and EOL conversation with a provider predicted 40% of the variance of preparedness for ACP (R^2=.40, F (3, 140) = 31.61, p<.001). Table 41 presents the regression coefficients, the t-test, and the 95% confidence intervals (CI) for odds ratios for each predictor of preparedness.

Table 41

Factors Predicting ACP Preparedness as Measured by APPS

Model #	Variable	*B*	*S.E.*	t	p	95% C.I.for EXP(B) Lower	95% C.I.for EXP(B) Upper
1	Acceptance	0.53	0.06	8.24	<.001	[0.40	0.66]
2	Acceptance	0.45	0.07	6.95	<.001	[0.32	0.58]
	Social DR[1]	-0.22	0.06	-3.78	<.001	[-0.34	-0.11]

3	Acceptance	0.43	0.07	6.70	<.001	[0.31	0.56]
	Social DR[1]	-0.21	0.06	-3.55	<.001	[-0.32	-0.09]
	EOL Convo[2]	0.16	0.08	2.05	0.04	[0.01	0.31]

Note: Dependent Variable = APPS; Variables entered in the model: Experiences ACP/AD, employed status, social support, social desirability, understanding mortality, Acceptance, Uncertainty, EOL Communication, All ADs, knowing living will, intent to complete AD in 30 days, intent to complete AD in 180 days

[1] Social DR= Social Desirability

[2] EOL Convo= EOL Communication

*

Summary of Correlates of APPS & Subscales

Advanced directive experiences were significantly positively correlated with APPS and all subscales (see Appendix M). Pearson correlations ranged from r=.14 to r=.25 in the subscales (p <.001). Having an AD and receiving information about ADs were also significantly positively correlated but knowing what an AD was not significant in psychological comfort and existential reflection subscales. APPS and its subscales were all significantly positively correlated with intent to complete an AD in 30 days. However, the thinking subscale was no longer correlated with an intent to complete an AD in 180 days, yet APPS and the remaining subscales remained positively correlated. Written and verbal EOL plans were all positively correlated with the APPS scale and all subscales except existential reflection. The thinking subscale was also not correlated with having a living will.

Not having experiences with ADs or being unsure was negatively correlated with APPS and the subscales. Interestingly, being unsure whether at EOL one would have a caregiver was also negatively correlated to APPS and its subscales while definitively having a caregiver at EOL was positively correlated to APPS and its subscales. Knowing that one did not have an EOL caregiver was inversely correlated with APPS but did not reach significance. Death of a loved one led to a correlation with willingness ($r=.12$; $p<.001$) but not with any other subscale or APPS itself.

Sociodemographic in terms of Hispanic origin, gender, religion, and education revealed correlations that demonstrate that preparedness for ACP is complex. Hispanic origin was significantly negatively correlated with APPS, desire to know and thinking. Female gender was positively correlated with willingness while male gender was negatively correlated with willingness. The gender gap supports prior research by Kim et al., (2021) which also found female participants were more willing to complete ADs. Participants whose religious beliefs effected their EOL decisions were positively correlated with APPS and its' subscales but those who had mixed beliefs effecting EOL decisions were negatively correlated to APPS. Participants in this study who were Muslim had significant positive correlations to APPs and all subscales except thinking. Agnostic and atheist participants were negatively correlated with psychological comfort. Participants educated with some high school (9th to 11th grade) were negatively correlated with APPS and subscales. In terms of life expectancy, participants who estimated their life expectancy at 6-12 months were positively correlated with APPS and all subscales.

Communication with a health care provider was significantly positively correlated with APPS and all subscales. Moreover, a specific EOL conversation with a health care provider was also significantly correlated with APPS and all subscales. Chronic illness was also positively correlated with preparedness and subscales. The correlation of APPS with EOL communication is promising for future research and practice. The correlations suggests that in chronic illness populations, health care providers should have routine AD discussion and EOL communication to foster preparedness for ACP.

Chapter Summary

This chapter describes the quantitative analysis of the Advance Planning Preparedness Scale. Analysis of demographics, expert panel review, pilot study, and full study were presented and reported. Correlations, multiple regressions, predictive modeling Exploratory Factor Analysis, Confirmatory Factory Analysis were presented and described. In addition, results of the analysis were discussed in relation to study aims, research questions and hypotheses. The APPS model appears promising in predicting intent to complete advance directives in six months which differs from the ACPRI scale.

Chapter V

Summary

The purpose of this study was to explore, develop and validate an instrument measuring preparedness for ACP, that is grounded in a thanatology theoretical framework and supports clinical nursing practice and knowledge development. In addition, to validation of the instrument, hypotheses investigated in this research examined the extent in which the newly developed Advanced Preparedness Scale, is supported by the Preparedness conceptual framework, and its relationship to communication, uncertainty, and acceptance.

This research study utilized CoSMIN methodology and Polit and Beck's method of developing a multi-item scale, to develop and validate the scale. The steps included conceptualizing the construct of advance planning preparedness, developing an item pool, evaluating the item wording, revising item readability, conducting content validity with experts and participants, pilot testing and full-scale testing of the advance planning preparedness scale.

In the testing phase, the new instrument was examined in the general population with existing instruments including MUIS_C, SHAI, ACPRI and PEACE scales. Test-retest reliability was examined using voluntary participation and recruitment on Amazon M-Turk, community facilities, churches, and community flyers. The study sample included individuals experienced with chronic illness and advance directives; a diverse expert panel (n=21) which included nurses, physicians, ethicists, and patients. The pilot study sample consisted of health care professionals and community members (n=88) and the full study sample consisting of a national sample of individuals with chronic illness experience (n=455).

The major findings of this study validated and supported reliability of the Advance Planning Preparedness Scale (APPS). The results of the studied identified an initial Cronbach's α of 0.954. Test-retest reliability was supported by a strong intraclass correlation (r=.945, p<.001). The results of the study also identified significant positive correlations between ACPRI, MUIS and both PEACE subscales. In addition, EOL communication was supported as an important variable for completion of advance directives. While APPS performance requires further testing in patient populations, several implications and recommendations implied by the results of this study are important to discuss.

Sample Demographics

The panel experts included nurses, physicians, ethicists, a palliative care provider and patients. The intent was to recruit individuals experienced with advance directives. The sample was comprised of the desired demographic in which the study intended to recruit. The average age was 57.8. However, the sample was predominantly female (n=17), Caucasian (n=18) and all had verbally left instructions related to EOL care. Despite verbalizing EOL care, only 64% (n=56) left written instructions with 80%(n=70) having a health care proxy, 53% (n=47) having a living will but only 1 participant with a MOLST. The expert panel was experienced with chronic illness with 60% (n=53) reporting a life limiting illness. Clark et al. (2018) suggested that individuals with serious illness, older than 50, female, and married were more likely to have an HCP. However, the expert panel may not have presented diverse ethnic or gender views.

The purpose of the pilot study was to examine feasibility of the pilot study. The pilot was recruited in a span of 10 days utilizing Amazon MTurk, flyers distributed in a Mid-Atlantic library and a community church in South. The use of Amazon MTurk allowed for a conveniently free large population (N=316) with a large sample (n=119) that met criteria for chronic illness. The pilot sample size (n=119) exceeded the target of 30. The demographics of the MTurk sample generally comported with what other studies have found (Boas, Christensen & Glick, 2020). The sample was predominantly married and 84% (n=100) of the sample was under 45 years of age. The length of the survey and the design may explain the attrition rate of nearly 22%.

In addition, the title of the survey "Advance Planning Preparedness" may have led to the overrepresentation of health care providers in the pilot panel. The pilot sample contained 46% (n=55) of healthcare workers, predominantly social workers composed 23% (n=27) of the pilot sample. The healthcare workers were experienced with ADs with 96% (n=52) of them reporting they had performed AD activities regularly with a mean of 4.35 times monthly. Healthcare workers were statistically different than the general population in terms of discussing and stating feelings about EOL as well as imagining EOL scenarios (Banner et al., 2019).

The pilot study mixed method design incorporated a qualitative survey to also evaluate comprehensibility and clarity of the items and instructions. Only 73% (n=85) of the pilot sample participated in the qualitative survey. Thick descriptions of the participants experiences and feelings were not obtained from their responses related to clarity of the items. In addition, three responses were potentially completed by participants that were either a robot or individuals copying and pasting from other sources. In general, respondents reported the survey was comprehensible and handled a difficult topic thoroughly. Only one respondent reported there were uncomfortable questions but did not elaborate. When respondents were asked for suggestions for improvement, it was suggested to rotate questions in the survey by two participants.

The full study was expanded to be representative of the general population. To incorporate a sample with older individuals, surveys were deployed in churches, community centers, Reddit and Classifieds.com in areas with older populations. In addition, it was suggested that missing responses could be prevented by deploying forced completion on the Qualtrics survey.

A test- retest cross-sectional design was utilized to recruit participants to complete the same survey used in the pilot study. Participants were recruited from Mid-Atlantic nursing homes, libraries, Reddit, Amazon MTurk, community organizations and churches. The expanded recruitment efforts recruited 4 diverse gender participants, but the sample remained predominantly young with only 6.5% (n=35) of study participants aged 55 or older. The sample also remained 51% (n=275) represented by health care providers with 94% (n=258) of them participating in AD activities on average 4 times monthly. Health care provider category was predominantly social workers (49%; n=133); physicians (16%; n=24); physician assistants (24%; n=66) and nurses (9%; n=25).

Tsai et al. (2022) supported that being a health care provider was positively correlated with ACP participation. Health care providers had a 3.18 (95% CI= 1.48-6.83) times to likely to have willingness to participate in ACP (Tsai et al.; 2022). This study did not support a correlation between health care provider status and the willingness subscale (Pearson r= -0.05; p=.89) but supported a positive correlation between preparedness and being a health care provider (Pearson correlation= 0.10; p=.02). Respondents who were health care providers were 1.6 (95% CI =1.11-2.34) times more likely to have an AD in this sample.

The survey design led to a dropout rate at each phase of the full study. Full study surveys were accessed by 1,144 participants, during the timeframe of 8/25/2022 to 11/2/2022. Of the full study population, 77% (n=783) met criteria of having a chronic illness and a total of 688 participants consented and met criteria for age and capacity to complete the study. After demographic questionnaire completion, there was a 23% dropout rate with 527 participants completing the APPS scale. A lower dropout rate occurred with each subsequent scale; a 3% dropout rate with 512 participants completing MUIS_C, a 2% dropout rate with 502 participants completing PEACE scale, a 3% dropout rate with 487 participants completing the ACPRI and a 1% dropout rate with 480 participants completing the SHAI. Of the 527 participants, only 475 completed all surveys for a retention rate of 90%.

The high survey response and retention rate may be possibly explained using web-based survey recruitment and in person recruitment strategies. Although the full study obtained a high response rate and survey retention rate, evaluating quality responses was a key issue for the researcher in the study. The researcher utilized several evidenced-based methods to remove biases that could be introduced by curt, robotic, or fake responses. Sánchez-Fernández, Muñoz-Leiva & Montoro-Ríos (2012) suggested evaluating number of replies, number of missing data, time spent completing the survey and stereotyped replies among others. This study specifically looked at the number of missing data of the survey, robotic responses, and duplicates. A total of 567 surveys from the pilot and full study were evaluated for analysis. The final sample to evaluate APPS was 543 surveys (full and pilot) with 24 surveys deemed to be duplicates by IP addresses or with poor response quality due to robotic and stereotypical responses. In this study, 75% of the survey participants completed surveys that met criteria for good response quality. In this study, therefore, response quality is related to respondents that completed surveys with completion times and responses that were not robotic.

The retest response rate faced many challenges in recruitment. Initially, participants were asked to identify an email address to receive a repeat survey in 48 to 72 hours. Participant response rates to retest emails and reminder emails were low. In the first month deploying the retest, only ten completed retest surveys were received from 275 surveys sent for a response rate of 3.6% The low response rate was incompletely explained by 2 surveys failing to be delivered and 36 emails bouncing. In addition, 10 percent (n=24) of surveys were started and abandoned. The recruitment campaign yielded a sparse participant retest pool of 22 participants. Follow-up emails were deployed with minimal improvement. A total of 854 emails were sent with 12% (n=101) of emails bouncing and .01% (n=8) failing. This response rate was only 4% with only 7% (n=55) starting the survey. Of those that started the completion rate was 40%.

The retest response rate was improved by deploying branching logic asking participants if they desired to retest. The sample size of 72% (n=177) who agreed to retest were immediately shown the Qualtrics address to access the retest survey. In addition, in the final week of the survey, the researcher printed business cards with the QR code to access the initial survey. Utilizing the anonymous link an additional 75 participants completed the survey. The anonymous link response rate was 42%. The response rate utilizing the deployed branching lock exceeded the 25% email response rate reported in the literature (Fernández et al., 2012). The total retest sample numbers were significantly lower than the initially desired sample of 225 participants as the newly deployed branching logic occurred in the final month of data collection.

Response quality was a persistent concern in the retest. Reminder emails and thank you messages were sent to participants. There is a clear need to determine if reminders or retest in general created participants that responded hurriedly to the survey, thereby providing lower or higher response quality. When comparing the timing of the full test to retest there was no statistical difference between the group means (t (1) =8.3, p=.077). Moreover, the 38 scale APPS was completed in both samples in less than 3 minutes.

The demographics of the study attempted to capture a wide range of individuals with chronic illness and advance planning. The sample size of 400 adults with chronic illness was decided a-priori to provide a large sample to support factor analysis and potentially subgroup analysis of the participants. Demographic data validated a diverse sample across race/ethnicities, gender, education level, religions, and chronic illness. Chronic illnesses were representative of the leading causes of US mortality; CAD (39%), Cancer (23%), diabetes (55%), stroke (25%), COPD (16%) and renal failure (20%). In this sample, 53% were aged 25-34 years old and 89% of participants reported experiences with ACP.

The younger age and increased AD experience in the study sample differed from other studies conducted by prior research. Yadav et al. (2017) in a systematic review of 150 studies found a random effect in their meta-analysis of Americans. The proportion of the population with any AD completion was 36.7 percent (95% CI: 33.3, 40.2). Meta-analyses also reported a completion rate for living wills of 29.3 percent (95% CI: 25.0, 34.0).

Von Blackenburg et al. (2021) in a German study performed a RCT in palliative patients to investigate the effect of motivational behavioral interventions on readiness for EOL conversations. In a subgroup sub analysis, younger participants (aged 18–35 years) and older participants (aged 65–88 years) were included in a mixed MANOVA to investigate the moderating influence of age on dependent variables “readiness,” “death acceptance,” “fear of death” and “fear of dying”. Age was determined to have no moderating effect on the effect of interventions. However, in univariate analysis age demonstrated a significant effect on readiness (F [1, 160] = 15.04, $p < 0.001$), death acceptance (F [1, 160] = 21.39, $p < 0.001$) and fear of death (F [1, 160] = 22.87, $p < 0.001$). Older individuals demonstrated a higher readiness for EOL conversations. In this current study, in univariate analysis age demonstrated no significant effect on readiness (F [1, 540] = .48, p=.489) or acceptance (F [1, 540] = .15, p=.696).

Young, Stone & Perre (2022) also conducted a cross-sectional quantitative study utilizing a convenience sample (n=30) of young graduate students to explore their readiness to complete ADs. The participants’ mean age was 24 (range 20-34) while two-thirds (60%) of the participants were white, and 27% were Black/African American. Results demonstrated that 87% of participants were comfortable discussing death and EOL and 63% were comfortable discussing their own death and EOL care.

The above literature suggests that preparedness for ACP and EOL communication is necessary to explore at all ages. Future studies are needed to explore APPS in older populations as an additional consideration in this study was participant understanding of the definition of AD. In this study, participants were asked about existence of written instructions about EOL, health care proxy, living will, MOLST and AD. Consistently, the number of participants acknowledging having either a MOLST (n=280), health proxy (n=313) or living will (n=331) were less than the number of participants that had knowledge of them. Yet, when participants were asked about the existence of having an AD; 267 participants stated yes, and 76 participants were unsure. This suggests 22% of participants were unsure if a

MOLST, health care proxy or living will equate with having an AD. Within group analysis revealed no statistical differences between the means of participants who stated yes or unsure regarding acceptance, readiness, or health anxiety. This finding that individuals complete ADs without understanding supports the grounded theory findings of Yonashiro-Cho et al. (2016).

An initial one-way between subjects ANOVA was used to assess the observed difference in preparedness, readiness, acceptance, and anxiety observed by those with, without and unsure of AD completion. The results of that analysis indicated that there was a statistical difference between having and not having an AD in relation to preparedness [F (2, 449) = 8.81, p <.001], readiness [F (2, 449) = 11.64, p <.001], and acceptance [F (2, 449) = 6.58, p =.002]. There was no statistical difference between having and not having an AD in relation to health anxiety [F (2, 449) = 2.32, p =.100]. Overall, further studies are needed to explore whether the type of AD influences preparedness.

Additionally, the study demographics supported a discrepancy in perception of severity of illness between patients and their clinicians. Demographically, 31% (n=166) of the sample reported being chronically ill or serious and terminal ill perceiving the possibility of having less than one to two years of life. Yet, 52% (n=280) had a MOLST form which is completed by health care providers who perceive patients to have less than two years of life. In a systematic review, Hancock, and colleagues (2007) revealed considerable discrepancies in patient and health care providers perceptions of awareness of prognosis and EOL. Researchers reported that patients may report less serious illness in the face of prognostic awareness.

Discussion

The central aim of this cross-sectional survey design was to develop and examine psychometric properties of the Advance Planning Preparedness scale. In this study, preparedness was conceptualized as a psychological state and attitude. The specific aims of the study are to examine the content validity, internal consistency, and re-test the developed APPS and evaluate construct validity.

Aim 1: Examine content validity

This study utilized COSMIN methodology for patient-reported outcome measures (PROM) to evaluate the content validity of APPS. The COSMIN methodology was developed in 2016 in a Delphi study among 158 experts from 21 countries (Terwee et al., 2018). Content validity is a fundamental important PROM measurement property and is defined by COSMIN as “the degree to which the content of an instrument is an adequate reflection of the construct to be measured”. Content validity can be conceptualized as three components: relevance, comprehensiveness, and comprehensibility. In this study, three key questions were ascertained as feedback during the content validity study. First, the relevance of the items for the construct of preparedness in patients with chronic illness? Second, the full comprehensive of APPS, or whether there was missing key aspects of the construct of preparedness for ACP? Third, the clarity of APPS, including the items’ wording and whether, understood by the target population as intended?

A total of 21 participants compromised of nurses, physicians, clinical ethicists, and patients completed the expert panel survey to examine content validity of the APPS. The aim of the expert panel was to eliminate ambiguous, irrelevant, and inappropriate items from the APPS instrument. The expert panel rated each of the 53 items in the newly developed APPS for relevance, comprehensiveness, comprehensibility, and clarity. For each item, I-CVI and S-CVI scores were calculated. Two items were revised for clarity and 15 items did not meet the .9 benchmark for I-CVI. No missing key aspects of ACP were identified by the expert panel. The resulting revised APPS was comprised of 38 items that were utilized in the pilot, full and retest studies.

As the researcher assessed content validity of APPS, other content validity studies undertaken in ACP readiness for individuals with chronic illness was also reviewed. The construct of ACP readiness within a TTM framework was evaluated by Sakai et al. (2022) and Berlin et al. (2021). The construct of ACP utilized in both studies were not applicable to APPS due to the international differences in culture and health care delivery models.

For example, Sakai and colleagues (2022) developed the *Readiness for Advance Care Planning Scale* (RACP) in Japan. Researchers conceptualized ACP from a literature review and utilized a 9-participant expert panel. Focus group panel meetings were utilized to obtain consensus regarding the appropriateness, representativeness, and explicitness of the items according to the following four perspectives based on TTM: pre- contemplation, contemplation, preparation, and action. A convenience sample of 6 patients between 30−60 years, chosen based on convenience, to commented on the face validity and the readability of each indicator. Data from the relevance, frequency, and importance ratings were not provided to assess risk of bias. Similarly, the content validity described by Berlin et al. (2021) included only qualitative research about ACP stages; EOL planning, barriers, and facilitators. Readiness was described as willingness to engage in EOL thoughts and conversations. Pilot testing was conducted. However, Berlin et al. (2021) did not provide information on clarity and relevance of the items to guarantee that all items were appropriate and comprehendible.

In summary, based on the COSMIN checklist, no studies exist that have assessed preparedness for ACP for all relevant items of measurement to prevent introduction of bias. The content validity evaluation of APPS in this study included patients and implemented the standards set by COSMIN.

Aim 2: Evaluate internal consistency and test-retest reliability of APPS

An internal consistency reliability analysis was performed using Cronbach's alpha for the APPS scale and its' subscales in the full study and retest. The Cronbach's alpha coefficients for the overall APPS was .95 for the full study and retest. Therefore, the instrument is reliable in measuring the latent construct of preparedness for ACP.

The subscale Cronbach's alpha coefficients ranged from .58 to .87. The intraclass correlation coefficients indicating test-retest reliability was .95 (95 CI .93-.96) for the total scale and ranged from .78-.83 for the five subscales. The weakest subscale was existential reflection. This was expected as the existential reflection scale only has four items with an ICC .78. Cronbach's alpha mathematically is a function of the number of items and the average inter-correlations among the items (Meyers et al., 2021). Therefore, Cronbach's alpha increases with additional the number of items or with increasing the average inter-item correlation.

This study demonstrated high reliability in the full study with better retest reliability than prior cross-cultural scales. For example, the RACP scale also purports a Cronbach's alpha of 0.95 (Sakai et al., 2022). The corresponding values for the RACP subscales ranged from 0.90 to 0.97. The ICC was 0.66 ($p < 0.001$) for the total scale and ranged from 0.52–0.65

for the five subscales. Thus, the APPS subscales demonstrate better inter class correlations than the RACP scale.

This study identified preparedness (readiness) as a predictor of ADs. Calvin created the ACPRI to measure readiness in a population of renal patients. In this study both APPS and ACPRI behaved similarly in terms of predicting the criterion of having an AD. Higher reliability was demonstrated in APPS (Cronbach's alpha=0.96) than ACPRI (Cronbach's alpha=0.84). Moreover, in individuals with chronic illness, ACPRI's reliability was better than the original study Cronbach's alpha of 0.73 (Calvin et al., 2006).

Aim 3: Evaluate construct validity

Exploratory and confirmatory factor analysis was conducted to examine the structure of the APPS developed instrument. An exploratory factor analysis of the 38 item APPS was performed on the data from 543 participant surveys of which no missing data was identified. The wording of item # 1 (I would feel uneasy if someone talked to me about end-of-life planning) suggested the need for reverse scoring. Item # 1 was eliminated utilizing Wald test for elimination.

Based on the theoretical framework, principal component analysis with Promax rotation with a 5-factor solution was used to analyze the first order structure of APPS. The five factors identified corresponded to the conceptualized model of preparedness for ACP. In the first and second order EFA, the factors loaded from first to last in the following order: 'psychological comfort"; "desire to know", "thinking", "willingness" and "existential reflection". In the initial EFA, items #2 and #6 were observed that were defined and matched to thinking and psychological comfort. Both items included concepts that could be defined by each factor. For example, item #2 discussed feeling “comfortable thinking” and item #6 discussed feeling okay “talking about planning”. The two items were eliminated because they did not contribute to a simple factor structure and failed to meet a minimum criterion of having a primary factor loading of .4 or above, and no cross-loading of .3 or above.

The recalculated Cronbach’s α of APPS-35 remained similar without the two items at .956, and repeated EFA without these items led to analysis with improved commonalities. The items were removed for further testing in the confirmatory factor analysis (CFA). Future research is necessary to evaluate perceptions of the wording of items in the scales. One possible explanation for the double loading of the items could be the interconnectedness between troublesome thoughts that lead to diminished psychological comfort and thinking about future ACP.

Both the 35 item and 37 item APPS appeared to capture the principal aspects of the Preparedness for ACP scale. Confirmatory factor analysis was conducted on three 5-factor models; the second order theoretical model (APPS 35) and the second order 5-factor models of the 35 item APPS. Model comparison revealed that the second order structure of the 35 item APPS with modifications was the best model comparison. The RMSEA .05, CFI .92, IFI .92, PNFI .81 and X^2/df=2.25 all indicate good fit.

The conceptual framework of the APPS was supported by the second order modified structure of the 35-item scale. The standardized regression weights demonstrated significant coefficients of each of the items and factors. The sample was diverse in terms of chronic illnesses but predominantly young. Future replications studies including older populations are necessary to validate the survey in elderly populations.

In this study, the theoretical model of ACP was supported. Preparedness (APPS-35) was predicted by uncertainty, acceptance, education and EOL conversation with a provider and accounted for 29% of the variance (R^2=.29, F (4, 446) = 44.59, p<.001) when social desirability was controlled for. Prior studies investigating emotional preparedness for death suggested prognostic awareness is a factor (Tang et al., 2019). Moreover, intrapersonal, and interpersonal factors are associated with ACP (Alano et al., 2010; Kim et al., 2018 & Kim & Lee, 2018). The theoretical model for APPS also includes awareness, social supports, and intrapersonal factors. The entire model was not tested in this study, yet the components tested accounted for approximately 29% of the variance of Preparedness for ACP.

Wang et al. (2022) similarly defined a construct of "readiness for ACP" as the extent of participants psychological preparedness to participate in informal ACP conversations without inclusion of the outcome of completing a formal AD. Their EFA demonstrated 59% of the variance of the scale by three factors; attitude; belief and motivation. The Cronbach's α was 0.923 and readiness was divided into a range of 4 quartiles. The developed questionnaire was specific to the Chinese cultural background and was limited by a small sample size carried out in one municipality in China. However, motivation to engage in ACP was not accounted for in the theoretical model of Preparedness for ACP but as an intrapersonal factor and antecedent. Future studies should evaluate motivation to test its relationship to preparedness.

Aim 3a: Hypothesis Testing

In this study, it was hypothesized that APPS would have a strong correlation (r > .7) with ACPRI. It was further postulated that APPS would have a moderate correlation (r

between .5 and .7) with the Struggle with Illness and the Peaceful Acceptance subscales of the PEACE. Furthermore, APPS was expected to have a moderate negative relationship (between -.5 and -7) with Mishel Uncertainty in Illness Scale (MUIS-C) scores and with the short health anxiety inventory (SHAI).

This study supported a strong correlation (r=.73, p<.001) between readiness as conceptualized by ACPRI and preparedness for ACP as conceptualized by APPS. In the theory of personal preservation, Calvin (2006) suggested that discussions that involve EOL preferences require individuals to weigh their responsibilities and risks while focusing on life and living. This appraisal involves talking and thinking about EOL which is consistent with factors in APPS. Originally designed for renal patients, ACPRI demonstrated a Cronbach's α of 0.73 (Calvin, 2006). In this sample, there were 108 renal patients. In renal patients, with ADs the Cronbach's α of APPS-35 is .95. This study supported the use of APPS-35 in readiness for multiple chronic illnesses.

This study supported a moderate correlation (correlation coefficient *r* between .5 and .7) with APPS-35, PEACE, and the Peaceful Acceptance subscale. However, this study demonstrated a weak correlation between APPS-35 and the Struggle with Illness subscale. The original validation study demonstrated that patients with awareness of terminal illness had a higher struggle with illness subscale score (Mack et al., 2010). This study had less than 1% of patients aware of terminal illness.

The PEACE scale was originally designed to measure the extent that patients with advanced cancer have a peaceful acceptance of their terminal illness. Mack et al. (2010) reported a Cronbach's α of 0.85 for the 12-item PEACE questionnaire with the subscales: a 7-item Struggle with Illness subscale (Cronbach's α = .81) and the 5-item Peaceful Acceptance subscale (Cronbach's α = .78). In this study, 123 participants reported having a cancer diagnosis. In cancer patients, APPS-35 had a strong reliability (Cronbach's α = .96). In addition, PEACE psychometric properties for the total scale were consistent with the validation study reported by Mack et al., (2010) however the subscales performed less reliably. Cronbach's α was 0.86 for the 12-item PEACE questionnaire with the subscales: Struggle with Illness subscale (Cronbach's α = .75) and the 5-item Peaceful Acceptance subscale (Cronbach's α = .71).

In the original validation study, Struggle with Illness scores were associated with some aspects of ACP (living will or healthcare proxy: mean scores, 13.9 vs 11.5; p= .02). Mack et al. (2010) could not determine causation between ACP and struggle with illness. Instead, Mack and colleagues hypothesized that patients who were struggling actively with issues around terminal illness may wish to make specific plans to ensure that their wishes are upheld. The current study demonstrates no significant correlation between struggle with illness and preparedness. Instead, as hypothesized, acceptance is correlated with preparedness.

This study supported the assumptions of Brown and colleagues (2017) that acceptance and willingness are components of readiness for ACP. Brown et al. (2017) developed the advance care planning readiness scale (ACPRS) in gynecological cancer patients. Readiness was positively correlated with acceptance as measured by the Peaceful Acceptance subscale (r=.55, p=.0005). This study also supported the correlation between peaceful acceptance and readiness (r=.50, p <.001). Unlike the ACPRS, this study did not indicate a negative correlation between readiness and struggle with illness. As this study did not isolate cancer diagnosis, future study in cancer patients is suggested.

In this study, health anxiety and fear of death were conceptualized as antecedents of preparedness for ACP. It was hypothesized that health-related worry, troublesome thoughts, awareness of physical changes, and feared psychological consequences of having an illness would negatively correlate with preparedness for ACP. Health related anxiety was measured by SHAI and postulated to correlate with preparedness moderately negatively.

In this study, SHAI and APPS were not correlated with each other. The SHAI scale was significantly correlated slightly with willingness (r=.09, p=.03) and existential reflection (r=.09, p=.03) subscale in the CFA model. As this study population had chronic illness, health anxiety as measured by SHAI may not capture fear of death. Health anxiety was found to have strong correlation with having an AD (Cramer's V=. 54; p <.001). However, health anxiety was not a measure that was significant in the outcome of EOL communication. Ostermann et al. (2022) proposed a cut-off value of 18 points for clinically significant health anxiety although empirical basis for this specific cut-off exists in the literature. In this study, SHAI had a mean value of 83.8 corresponding to a cut off value below 18 points. Thus, there may have been nonsignificant clinical health anxiety. Future studies are necessary in other populations utilizing other instruments that may capture death attitudes.

Similarly, to struggle with illness, this study does not support troublesome thoughts, fear of psychological changes or awareness of illness as correlates of preparedness. As preparedness for ACP was hypothesized initially as a death attitude, future study should investigate whether fear of death and death acceptance are correlated with preparedness for ACP.

Uncertainty as measured in this study by MUIS_C also did not negatively correlate with preparedness. Zwakman et al, (2018) reported that the impact of uncertainty on preparedness for ACP could vary depending on if uncertainty results in positive or negative feelings. In this study, participants were not queried about their feelings related to ACP. Cronbach's α was .83 with mean scores of MUIS_C were 73.2 (SD 12.4) with a range of 29 to 98. In the original validity scores with patients with chronic illness the mean score was 57.1 (SD 17.6) with a Cronbach's α of .91.

In this study, only 20% (n=84) of participants who had an AD reported being uncertain about their diagnosis. The MUIS_C score for those who were uncertain was 74.7 (SD 12.6) and not statistically different than the sample population. Rains et al. (2015) supported that uncertainty moderates the appraisal intensity that concludes with information seeking desire. Rains et al. (2015) suggested the explanation could be traced to participant's motivation. In this study, uncertainty and preparedness were significantly correlated in individuals with ADs (Pearson correlation = .18; p=.003). These results suggests that appraisal could be a potentially moderating or mediating factor. Emotional readiness has a weak but positive relationship with uncertainty suggesting that other mechanisms such as the appraisal of uncertainty may explain emotional preparedness related to existential reflection. Given the potential for individuals to appraise uncertainty differently, in future study it would be worthwhile to explore appraisal and preparedness to ascertain whether level of uncertainty is associated with different levels of preparedness.

This study suggests that uncertainty itself does not negatively affect preparedness but rather the appraisal related to uncertainty may have a role. Brashers & Hogan (2013) discussed the implications of appraising uncertainty on information seeking. According to theories of communication and uncertainty management people seek and avoid communication based on their positive, negative, or neutral views. Future study should utilize a measure designed to capture thoughts and feelings indicative of change in life view such as Growth Through Uncertainty Scale (GTUS) (Mishel & Fleury, 2001). Alternatively, rather than utilizing the one factor MUIS_C, the use of the 4 factor MUIS_A may enable future research to determine if preparedness for ACP correlates with Mishel (1988) identification of ambiguity, complexity, inconsistency, or unpredictability subscales of MUIS_A.

The theoretical model was evaluated in hypothesis testing utilizing stepwise linear regression. After adjusting for social desirability, acceptance and EOL communication predicted 40% of the variance of preparedness for ACP (R^2=.40, F (3, 143) = 31.61, p<.001). The theoretical model is complex and includes variables that were not examined in this study. Fear of death as well as external factors (e.g., decisional conflict; societal influences) are hypothesized to influence APPS. Future studies are necessary to determine the influences of these and other variables on preparedness.

Aim 4: Evaluate criterion validity

This study hypothesized that APPS would demonstrate prediction of the actual outcomes of ACP (such as signed AD, living will, health care proxy, durable health power of attorney, MOLST etc.). In this sample, 49% (n=267) reported having an AD. Reliability of the APPS scale in individuals with ADs was excellent (Cronbach alpha=.952). The study utilized binary logistic regression to determine prediction of ADs. Preparedness alone predicts only a small variance of AD completion. This supports that completion of ADs is complex.

Initially, multiple regression analysis was utilized to review whether the theoretical model of preparedness predicted having an AD. Preparedness in combination with EOL communication predicted a participant was three times more likely to have an AD (Exp B=

3.14, 95% CI =2.24,4.38). Preparedness led to a higher odds ratio (ExpB =1.15) to have an AD than EOL (ExpB=.78) in the regression model. However, when social desirability was controlled for preparedness ceased to be significant. Past experiences with AD/ACP, routine discussion and EOL communication had significant odds ratios ranging from 1.8 to 3.7. Prior studies by Wang et al. (2022) identified three dimensions of ACP readiness; attitude to ACP, belief in participating in ACP and motivation for ACP. As this study, isolated attitudes for ACP the results of this study represent a unique component of preparedness. Future study should investigate whether higher scores in APPS correlate with motivation for ACP.

Correlations between APPS and variables demonstrated the importance of having a health care proxy. Having an HCP is correlated with APPS (r=.18; p <.001). An initial one-way between subjects ANOVA was used to assess the influence of an HCP on preparedness. Having a health care proxy met significance for interaction with preparedness [(F 1, 293) =5.35, p=.021]. This finding supports earlier research by Ko et. al (2016) that a health care proxy in combination with attitudes toward ACP is a significant predictor of AD completion (OR=1.18; 95% CI=1.00-1.39).

This study postulated that sociodemographic, intrapersonal, and external influences are modifying factors of death attitudes that mediate preparedness for ACP. In this study sociodemographic data including race, ethnicity, gender, and income were collected along with religious affiliation. Prior studies supported race/ethnicity, number of chronic health conditions, experiences with AD, age, female gender, and higher education as correlates of AD completion and ACP (Alano et al, 2010; Choi, McDonough, Kim & Kim; 2020; Kim et al., 2021; Rao et al., 2104; Wang & Sheng, 2022). In this study, gender was correlated with preparedness (r=.09; p=.05) but there was no statistical difference between genders in relation to AD completion. In this study having an AD was (r=.26, p<.001) correlated with past experiences with AD and correlated (r=.18, p< .001) with preparedness. Preparedness was correlated as well with number of chronic illness and higher education as well as gender. Hispanic ethnicity was negatively correlated (r=-.09, p=.04) with preparedness.

In this study, religiosity was included as an intrapersonal factor that effects preparedness, uncertainty, and death attitudes. Dobbs et al. (2012) found religiosity and fear of death were associated with ACP when physician EOL communication was accounted for in a sample of elderly community adults with chronic illness. In their study, self-reported religiosity had only a 0.68 higher likelihood of an ACP discussion with physicians (Dobbs et. al, 2012).

End of life communication was supported as an important factor in ACP. Findings from this study supported that people who had AD were 12 times more likely to have had EOL communication with a health care provider. Findings from the study indicated individuals with preparedness and EOL communication were nearly twice as likely to complete ADs. These findings support qualitative research findings articulated by Zwakman et al. (2020). Preparedness is iterative and may shift with EOL conversation. Zwakman et al. (2020) suggested that health providers should initiate EOL conversations regardless of the patient’s state of readiness. More important is the ability of the clinician to alter the conversation with the patient’s awareness and state of preparedness. Future study should assess changes in the level of preparedness for ACP with differing clinician expertise of communication.

The association between clinician patient communication and preparedness was hypothesized more than a decade ago by Wentlandt and colleagues. In univariate analysis, clinician patient communication was associated with better preparedness (*B*(SE)= -2.995(.37); p<.001) (Wentlandt et al.; 2011). However, communication was not separated between prognostic communication and EOL communication. This study differentiated communication about ADs from EOL communication.

In this study both EOL communication and discussion about ADs were significantly correlated (r=.39, p<.001). Yet, preparedness was correlated with AD communication (r=.13, p=.003) less than with EOL communication (r=.19; p=.000). In this sample, discussing ADs with a health provider was a significant predictor of APPS (F (1) 8.92, p=.003) but only accounted for 2% of the variance of APPS (R2=.017 adjusted R2=.015). Preparedness was a significant predictor of EOL communication (F (1) 19.11, p<.001) but only accounted for 3% of its' variance (R2=.035 adjusted R2=.033). Future studies should investigate the relationship of routine AD communication and EOL communication to ascertain mediating and moderating relationships with preparedness. Testing additional variables postulated as antecedents of preparedness will be important in future studies.

As prior research has supported, EOL communication was correlated with preparedness for ACP. Interestingly, in this study, stepwise logistic regression demonstrated participants with perception that their religious affiliation effects EOL decisions were 1.8 times more likely to have EOL discussions with their providers (p<.001). Participants were also twice as likely to have EOL discussions if they had struggle with illness (p=.002) and 1.7 times more likely to have EOL discussions if they had preparedness (p=.009). Table 42 displays the stepwise logistic regression model that demonstrates EOL as an outcome of the theoretical model of ACP.

Table 42

Stepwise Logistic Regression Model for EOL Discussions with Provider Model

Characteristic	β (SE)	OR	p
Religion affects EOL decisions	.602 (.143)	1.825	<.001**
Uncertainty	.010 (.193)	1.010	.960
Acceptance	-.309 (.241)	.734	.201
Struggle with Illness	.680 (.217)	1.973	.002**
Health Anxiety	.117 (.095)	1.124	.218
Preparedness	.550 (.210)	1.733	.009

Model Summary: Nagelkerke's R^2 0.14 p<.001**

Note. B = estimated unstandardized regression coefficient, SE = standard error, OR = Odds Ratio 1df= degree of freedom.

Findings from this study supported three significant predictors of AD completion: past experiences with AD/ACP, EOL communication and discussing ADs with a health care provider. This study supports earlier findings of Alano et al. (2010) which demonstrated increased odds of completing an AD in persons who had received information about or had been asked to complete ADs. Bischoff and colleagues (2013) also examined an elderly (mean age 82.6) longitudinal Health and Retirement sample and found associations between ADs, ACP discussions and a written durable power of attorney. This association suggests the importance of nurses providing education about AD documents as well as supporting providers to begin AD discussions.

Hypothesis 1: The Advance Planning Preparedness Scale will have better criterion validity than the ACPRI?

In this study, participants were surveyed related to the criterion of having an AD. Both surveys behaved similarly. Correlations related to AD discussion and EOL communication were also examined. Both ACPRI and APPS were exactly correlated to EOL conversations with HCP (r=.19, p<.001). Routine discussions related to AD were also similar. The APPS was correlated with AD discussion (r=.13, p=.003) and ACPRI was equally correlated with AD discussion (r=.14, p=.001).

Calvin (2004) first developed the pool of items based on her grounded theory of self-preservation. Specifically designed for renal failure patients, the theory of self-preservation, two components helped "define individuality": knowledge and personal beliefs. This study supports Calvin (2004) assumptions that personal attitudes are related to readiness for advance directives. This study differs from Calvin's research in that it advances EOL research in more than one specific illness. Unlike the ACPRI, APPS was developed to be applicable in multiple chronic illnesses. The utility of the Preparedness Theoretical Model is also future use in healthy adults. The APPS was developed appreciating attitudes related to thanatology and social-cognitive responses to appraising EOL.

This study focuses on the patient's individual response to their appraisal of EOL. This differs from the items discussed in the ACPRI. Calvin (2006) viewed patient readiness in response to participant perception of interaction with physicians and nurses and their relationships with family and friends. Although the ACPRI behaved similarly in predicting the AD criterion, the items in APPS are focused on the internal perceptions of the participants and not external relationships with health professionals and family.

This study is the second study to reference the ACPRI in the development of a tool to examine readiness. Sakai and colleagues (2022) developed the Readiness for Advance Care Planning (RACP) scale utilizing a web-based recruitment of 624 Japanese participants. Five factors based on the behavioral model framework of TTM were identified; intent to write, intent to talk, preparations for the behavior, practice of talking and writing, and recognize the importance of talking and writing. Cronbach's α was 0.95 with ICC of 0.66 ($P < 0.001$) for the total score and ranged from 0.52 to 0.65 for the five subscales, indicating moderate agreement. The study had limited information about the nature of chronic illness participants had or participant awareness of ACP. In addition to not having cross cultural validity, researchers view readiness as a behavior rather than a psychological attitude.

In sum, ACPRI and APPS in this study predicted the criterion of having an AD similarly. The construct of APPS focuses on the internal perception of psychological preparedness for ACP while ACPRI items address external relationships with health care professionals. Future study is necessary utilizing actual measurement of the criterion in interventional study to examine differences between both instruments.

Hypothesis 2: The correlation of social desirability with APPS is significantly lower than that with ACPRI.

The correlation of the APPS scale with social desirability, as measured by SDRS5, was lower than ACPRI. Both scales were negatively correlated with social desirability which was expected. Social desirability bias is generally defined as providing responses that are perceived as more acceptable than the response that the participant would have ordinarily answered. This study utilized the SDRS-5 to control for bias related to social desirability. As ACPRI and APPS were closely correlated it was not surprising that social desirability differences were small.

In summary, these findings suggest that self-report data resulting from web-based survey appear to be valid. Methods to assess socially desirable responses and reduce bias are important because unintended responses can be introduced when reflecting on sensitive EOL topics. Potential sources of measurement error, including that introduced by the participant, has implications not only for this study findings, where it might lead to erroneous results, but also for future AD program intervention development. Future study should also include social desirability tools for the above reason.

Limitations

This study is a factor analysis and first test of an original theoretically grounded model based on how death attitudes influence individuals with chronic illness preparedness to complete ADs. The study utilized regression models to contribute to the state of the science on ACP and EOL to conceptualize the roles of uncertainty, acceptance, readiness, and anxiety. Importantly, the conceptual model significantly explained the factors related to predicting preparedness. The present study has some further limitations.

First, the identification of the domains of psychological comfort, thinking and existential reflection demonstrated overlaps between the constructs. Despite the inductive approach and concept analysis, the researcher's experience in bioethics and palliative care led to an improper layperson conceptualization of the domain. The sample included a significant number of healthcare professionals who may have equally distorted the definition. Tripken et al. (2018) discussed the importance of basic vocabulary and knowledge to fully engage in ACP. In this study, 40% (n=216) of the population reported not knowing what an AD was. This lack of familiarity and knowledge of ACP explains the discrepancy between the 49% (n=267) of participants who reported having an AD and the 61% (n=331) of participants who reported having a living will. Future studies may need to clarify the wording and define the meaning of ADs prior to administering the demographic survey and other survey instruments.

Secondly, the sample was homogenous in many aspects. For example, 50% (n=269) of the participants had ADs. Considering that, during recruitment, the study participants were recruited in community facilities and online, the sample were potentially more open to EOL communication and advance planning than the average population. This self-selection bias limits the generalizability of observed mean scores.

In addition, common method bias may be a concern as the data in the current study came from instruments with self-reported data. This study measured social desirability to offset this bias. The mean and median score of the Socially Desirable Response Set-5 was 11 indicating that some participants did respond to questions along a perceived societal norm. Self-report about knowledge and existence of ADs could have led to under or overestimation in this study. Future study will recruit participants in person and perform focus groups to obtain additional qualitative data on the perception of the items in APPS.

The sample was not representative of participants of ages older than 65 who have more prevalent chronic diseases. Older individuals may not have initiated the study because of internet recruitment, a lack of interest, time concerns and/or severity of physical symptoms or psychological distress. Younger individuals with chronic illness have other views of uncertainty. Sharkey et al. (2019) demonstrated that uncertainty in chronic illness as measured by MUIS_C in college aged individuals was represented by only two factors: Ambiguity/Future Uncertainty *($\alpha = .93$),* and Unpredictability *($\alpha = .89$).* In addition, symptom burden could not be ascertained from the anonymous sample. Mack et al. (2018) demonstrated that higher symptom burdens effect acceptance. Larger, more diverse samples of individuals is an important direction for future research to establish external validity and generalizability of the model in this dissertation as well as to explore potential differences in hospital settings particularly palliative care.

The cross-sectional survey test-retest design prevented the exploration of the causal relationship between ACP preparedness and the related factors. Thus, further validation studies are needed. The cross-sectional data also prevented an ability to draw temporal conclusions and the retest sample did not reach the intended participant number. The study hypotheses were carefully considered, and more meaningful observations may be obtained in future longitudinal studies. Future, post-hoc analyses will be conducted to observe moderating, mediating, or bidirectional relationships and to test alternative hypotheses.

Finally, the assumptions and weaknesses of structural equation modelling (SEM) methodology led to errors in model fit. Structural equation modelling for the unobserved APPS latent variable required that the (a) APPS scale be both continuous and normally distributed; (b) sample size was sufficiently large to create a reliable estimation of the related correlation matrix; and (c) number of observed variables is kept to a minimum (Byrne, 2013). The theoretical model when tested led to inadmissible solutions that were deemed less than adequate with discordant measures of fit with AIC and BCC. This problem was surmised to arise from the large number of observed variables (37 observed) in this study and the large number of thresholds. The use of the maximum likelihood model and bootstrapping aided these limitations. Future study may need to engage a larger diverse pool of participants to reduce the likelihood of the SEM of having cells comprising zero to near-zero cases that created the errors in this study.

In this study, BIC proved to be a better fit index than AIC in the model. When AIC between the model and the saturated model were compared, AIC in the saturated model was lower. Saturated models overparameterize and interpolate the data creating extremely high-variance predictors (Rocks & Mehta, 2022). For example, in the final model the number of parameters (NPAR) in the saturated model was 630 while the final model had an NPAR of 76 parameters. As APPS-35 is a predictive model of ACP, BIC fit indices had a propensity of choosing the parsimonious model as it applies a greater penalty to models that are complex. Future replication studies in other populations should examine additional CFA models to ascertain whether shorter versions of the APPS-35 retain predictive properties.

In addition, future study should consider the temporal nature of ACP. The theoretical model suggests ACP is iterative and preparedness is influenced by EOL communication such that a threshold of readiness culminates in completion of an AD. Inferential statistics related to the temporal nature of ACP could not be performed from cross-sectional data and future study should utilize repeated measures longitudinally to ascertain whether preparedness increases over time.

Finally, because the relevant factors included in APPS was the subject of development and validation, the ability to predict AD completion as evidenced by the value of R squared is relatively low for the included variables in the multiple linear regression model. The relevant factors included in preparedness have still not been evaluated. For example, motivation and the intrapersonal factors that were antecedents to preparedness were not tested in this initial validation study. Future experimental designed studies will be required to observe the outcome variable of ADs. Future studies should address the study limitations to reinforce and support the results achieved in this study.

Implications to Nursing Practice & Education

In the United States, approximately 90 million people live with serious life-threatening chronic illness. The strength of the APPS tool is that it is a highly reliable and valid tool based on the theoretical framework of preparedness as an iterative non-binary measure. Both in clinical practice and education, EOL care is important.

In nursing education, it has been recommended to include EOL care and palliative nursing. Nurse educators have a unique opportunity to improve the care of patients with chronic illness and their families by providing EOL education to their mentees and learners. In 1999, the SUPPORT trial identified improved EOL communication as a priority for health professionals. Now two decades later, the American Association of Colleges of Nursing (AACN, 2021) has identified core competencies in nursing that requires educators to address EOL skills. The current essentials in nursing education suggests a competency-based assessment. Findings from this study, support of temporal nature of preparedness. Readiness for communication about ADs and the theoretical framework of preparedness for ACP can be included in nursing programs to optimize nursing assessment and improve patient AD communication. Learning assessments should appreciate the longitudinal nature of developing competency in nursing rather than a cross-sectional traditional assessments that only measures outcomes in a finite manner.

National policy programs have promoted the adoption of frameworks for ACP. The MOLST/POLST framework is the most frequent paradigm to address ACP through shared decision making. Initiating MOLST begins with preparations for the discussion (Bomba, 2012). The use of APPS has implications to aid policy developers in including a validated measure of patient readiness to address ACP. Findings from this study support collaborative decision making. Moreover, the American Nurses Association (ANA, 2019) revised its interpretative statements and suggested "Nurses...must be comfortable supporting patients with end-of-life conversations, assessing the context of a medical aid in dying request...remain objective when discussing end-of-life options with patients who are exploring medical aid in dying [and] have an ethical duty to be knowledgeable about this evolving issue." The APPS scale can support an objective measure to help nurses feel comfortable to uphold this duty to discuss EOL and AD.

In April 2023, the National Academies of Sciences, Engineering, and Medicine will conduct a public workshop to explore issues related to supporting and sustaining the workforce to care for people with serious illness. A key issue of burnout is related to the moral distress of nurses when patients are perceived to suffer. Nursing administrators and other stakeholders can aid nurses in advocating for adoption of patient's EOL wishes. The APPS scale may have utility in being adopted into electronic medical records and nursing workflows to indicate patient readiness for AD discussions.

In addition, to improving the ability for nurses to advocate for early discussion of AD. The APPS instrument has the potential to improve the quality of patient care. Advanced directive discussions require patients to share in medical decision making. A key ethical implication is the ability of the person to exercise their own substituted judgment related to EOL and relieve caregiver burden of judgments that decline life sustaining treatments.

The American Nursing Academy and National Academies of Medicine in collaboration support the development of community-based models of care delivery for people with serious illness. In 2017, the cost of healthcare expenditures for individuals with serious illness in communities was 1 trillion dollars. Utilizing APPS to determine readiness for ACP in communities could encourage earlier AD discussion prior to hospitalization and improve efficiency and utilization of ICU care. More importantly, diminish unwanted aggressive treatment in favor of improved autonomous patient care.

The determination of psychological readiness will aid nurses to professionally optimize the ontological definition of nursing. Nurses address the phenomenon of psychological readiness through their compassionate presence. The definition of nursing was revised in 2021 to address the duty of nurses to alleviate suffering.

> "Nursing integrates the art and science of caring and focuses on the protection, promotion and optimization of health and human functioning; prevention of illness and injury; facilitation of healing; and alleviation of suffering through compassionate presence. Nursing is the diagnosis and treatment of human responses, and advocacy in the care of individuals, families, groups, communities, and in recognition of the connection of all humanity." (ANA, 2021)

The APPS will aid nurses in recognizing psychological readiness when performing nursing specific interventions.

This study adds to the body of nursing research. Walczak et al. (2016) suggested that prior to an EOL discussion people feel that both clinician and patient readiness is necessary. For the patient, this means that the desire to know overrides fear or ambivalence about discussing EOL. For the clinician, this means having the expertise to communicate. Prior research has concentrated on clinician and nurse comfort with EOL communication and patient's behavioral stages of change. This is the first study to concentrate on patient's readiness as a psychological attitude investigating the individual's desire to know and psychological comfort with ACP discussions.

Recommendations

This study focused on preparedness for ACP and concluded that EOL communication is an important factor in AD completion. Several studies have supported the barriers of clinicians in engaging patients in ACP; including clinician competence; fear of dispelling hope and prognostic uncertainty (Killackey et al., 2019; Paladino et al., 2020). Given the importance of communication to preparedness for ACP, this study supports the need for developing training programs to improve EOL conversation skills of nurses, physicians, and other healthcare providers. The APPS-35 through identification of patients with higher preparedness for ACP could encourage providers to begin earlier conversations and alleviate provider fear to begin conversations.

Sudore et al. (2018) created an Organizing Framework of ACP and rated readiness to engage in ACP as a key construct. The optimal timing to begin conversations particularly for those without serious illness is unknown and elusive (Brighton et al., 2016). Validated measures for the construct, conceptualized by this study as preparedness, was lacking when the multidisciplinary Delphi panel identified the framework. This study is an important step as it has validated and developed an operational definition for preparedness for ACP as a psychological state. The APPS provides a context for analyzing patient and community population psychological preparedness.

Elusive components of ACP in creating patient centered structured ACP programs are the optimal timing for AD discussions and the actual psychological state of readiness for EOL communication. The concept of preparedness in this study suggested there is a threshold level of preparedness that overrides fear and ambivalence. Temporality (timing) was also not investigated in this study but acknowledged as an important contributor to readiness for clinicians to begin ACP conversations and patients to become ready to engage in ACP. It may be that preparedness for ACP is not fixed but can be altered with time, longitudinal illness experience and ongoing AD discussions. Future investigations and clinical use of APPS should monitor changes in psychological readiness for ACP over time. Further research is also needed to assess the sensitivity and specificity of the instrument to detect preparedness changes in response to the trajectory of patient's illnesses as well as ACP interventions.

Significance to Nursing

Preparedness to have a conversation about EOL is viewed as a prerequisite for ACP. In the past decade, and in response to the recent COVID-19 pandemic, there has been a national call to begin EOL conversations earlier along the trajectory of chronic illness. Numerous studies have focused on skills, abilities, and timing of clinician communication. Healthcare clinician's uncertainty about patient readiness to engage in EOL conversations is a potential barrier to initiating ACP. Other provider barriers include fear of causing patient distress and personal discomfort with death (Myers et al., 2018). This study aimed to create and validate a tool for clinicians and researchers to assess patient preparedness for ACP. Future use of this tool may alleviate clinician distress and address their internal barriers to discussing ADs.

The developed scale also expands the concept of uncertainty postulated by the late Merle Mishel. A component of uncertainty is correlated with preparedness. Positive appraisal of uncertainty leads to a threshold that potentially fosters preparedness for ACP. The developed APPS-35 scale has utility in both nursing practice and research.

In clinical practice it is important to design tailored interventions that may be personalized for the patient's state and level of readiness. Future study on the concept of preparedness for ACP can be utilized to develop clinical practice guidelines for structured ACP programs. In practice, the APPS-35 can be utilized as a scale to indicate preparedness and stimulate EOL communication.

Preparedness for ACP is an important assessment in ambulatory, community, long term care settings and hospital-based practice. In future research, the APPS-35 is designed for implementation in a diverse cultural body to understand the preparedness for ACP as an attitude that influences EOL communication and AD completion. The APPS-35 can be utilized in future qualitative and experimental designs to understand the mediating, modifying and moderating effects of intrapersonal and social factors on preparedness. As a validated scale, intervention programs that promote ACP can be researched.

Conclusion

In this study the psychometric properties of the APPS-35 were developed and evaluated. The reliability and validity were supported by Cronbach's alpha coefficients, intraclass correlation coefficients, factor structures and the significant relationship of the subscales in the theoretical model. Preparedness has been theorized as a behavior and this is the first study to attempt to validate ACP as an attitude in Western cultures.

The purpose of the study was to develop and validate a new instrument, the APPS, to assess preparedness for ACP. The instrument demonstrated validity and reliability. The instrument can be utilized for various purposes in nursing research, policy, and practice, such as encouraging EOL conversations with health care professionals. The instrument may find utility in measuring ACP outcomes in research and practice.

Originally, a 38-item version of APPS with 5 subscales was developed to assess preparedness for ACP in community participants with advanced chronic illness. The scale was revised and modified to 35 items and retained psychometric properties that demonstrated excellent validity and reliability. The supported validity and reliability of APPS-35 in this study provides insight into preparedness as an attitude in the community at large. Assessment of preparedness for ACP, may facilitate understanding of the appropriate timing for EOL communication. Further studies are needed to examine the clinical utility of APPS in additional populations and settings.

References

Abramowitz, J. S., & Braddock, A. (2008). *Psychological treatment of health anxiety and hypochondriasis: A biopsychosocial approach*. Hogrefe publishing.

Abramowitz, J. S., Deacon, B. J., & Valentiner, D. P. (2007). The Short Health Anxiety Inventory: Psychometric properties and construct validity in a non-clinical sample. *Cognitive Therapy and Research*, *31*, 871-883.

Alano, G. J., Pekmezaris, R., Tai, J. Y., Hussain, M. J., Jeune, J., Louis, B., ... & Wolf-Klein, G. P. (2010). Factors influencing older adults to complete advance directives. *Palliative & Supportive Care*, *8*(3), 267-275.

Alberts, N.M., Hadjistavropoulos, H.D., Jones, S.L., Sharpe, D. (2013). The Short Health Anxiety Inventory: a systematic review and meta-analysis. J Anxiety Disord;27(1):68-78. doi: 1.1016/j.janxdis.2012.1.009. Epub 2012 Nov 9. PMID: 23247202.

Allen, J. Y., Hilgeman, M. M., & Allen, R. S. (2011). Prospective end-of-life treatment decisions and perceived vulnerability: Future time left to live and memory self-efficacy. *Aging & Mental Health*, 15(1), 122-131. doi:1.1080/13607863.201.505229

American Association of Colleges of Nursing. (2021). The essentials: Core competencies for professional nursing education.

American Nurses Association. (2019). The nurse’s role when a patient requests medical aid in dying. Nursebooks.org

American Nurses Association. (2021). *Nursing: Scope and standards of practice* (4th ed.). Nursebooks.org.

American Psychological Association (2007). *APA dictionary of psychology*. American Psychological Association.

Amjad, H., Towle, V., & Fried, T. (2014). Association of Experience with Illness and End-of-life Care with Advance Care Planning in Older Adults. *Journal of the American Geriatrics Society*, *62*(7), 1304-1309.

Arifin, W. N. (2022). Sample size calculator (web) [software]. https://wnarifin.shinyapps.io/ss_sem_cfi_unequal/

Arnett, K., Sudore, R. L., Nowels, D., Feng, C. X., Levy, C. R., & Lum, H. D. (2017). Advance care planning: understanding clinical routines and experiences of interprofessional team members in diverse health care settings. *American Journal of Hospice and Palliative Medicine®*, *34*(10), 946-953.

Au, D. H., Udris, E. M., Engelberg, R. A., Diehr, P. H., Bryson, C. L., Reinke, L. F., & Curtis, J. R. (2012). A Randomized Trial to Improve Communication About End-of-Life Care Among Patients with COPD Intervention to Improve End-of-Life Communication. *CHEST Journal*, 141(3), 726-735.

Babrow, A. S., Hines, S. C., & Kasch, C. R. (2000). Illness and uncertainty: Problematic integration and strategies for communicating about medical uncertainty and ambiguity. *Explaining illness: Messages, strategies, and contexts*, 41-67.

Banner, D., Freeman, S., Kandola, D. K., Meikle, M., Russell, B. K. M., Sommerfeld, E. A., Flood, D., & Schiller, C. J. (2019). Community perspectives of end-of-life preparedness. *Death Studies*, *43*(4), 211–223. https://doi.org/1.1080/07481187.2018.1446060

Barnes, S., Gardiner, C., Gott, M., Payne, S., Chady, B., Small, N., ... & Halpin, D. (2012). Enhancing Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature. *Journal of Pain and Symptom Management*. 44(6): 866-879.

Bayer, W., Mallinger, J.B., Krishnan, A., et al. (2006). Attitudes toward life-sustaining interventions among ambulatory black and white patients. *Ethnicity and Disease,* 16, 914–919.

Becker, E. (1973). *The denial of death*. New York: Free Press Paperbacks, Simon & Schuster.

Bender, M., Huang, K.N., & Raetz, J. (2021). Advance Care Planning During the COVID-19 Pandemic. *J Am Board Fam Med*. 34(Suppl): S16-S2. doi: 1.3122/jabfm.2021.S1.200233. PMID: 33622811.

Berlin, P., Leppin, N., Nagelschmidt, K., Seifart, C., Rief, W., & Von Blanckenburg, P. (2021). Development and validation of the readiness for end-of-life conversations (REOLC) scale. *Frontiers in Psychology*, *12*, 662654

Berlin, P., Seifart, C., & von Blanckenburg, P. (2022). Validation of the Readiness for End-of-Life Conversations (REOLC) scale in a German hospital setting. *PEC Innovation*, *1*, 100045.

Berman, A. (2015). A nurse with fatal breast cancer says end-of-life discussions saved her life. *Washington Post.*

Bernacki, R. E., & Block, S. D. (2014). Communication about serious illness care goals: A review and synthesis of best practices. *JAMA Internal Medicine, 174*(12), 1994–2003. https://doi.org/1.1001/jamainternmed.2014.5271

Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. *Journal of the American Geriatrics Society*, *61*(2), 209–214. https://doi.org/1.1111/jgs.12105

Boas, T. C., Christenson, D. P., & Glick, D. M. (2020). Recruiting large online samples in the United States and India: Facebook, mechanical turk, and qualtrics. *Political Science*

Research and Methods, *8*(2), 232-250.

Bomba, P. A., Kemp, M., & Black, J. S. (2012). POLST: An improvement over traditional advance directive. *Cleveland Clinic Journal of Medicine,* 79(7), 457-464.

Bora, S. T., & Buldukoğlu, K. (2020). Case Report Using the Uncertainty in Illness Theory to provide care for the caregiver: A case report.

Brashers, D. E., & Hogan, T. P. (2013). The appraisal and management of uncertainty: Implications for information-retrieval systems. *Information Processing and Management*, *49*(6), 1241–1249. https://doi.org/1.1016/j.ipm.2013.06.002

Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons Living with HIV or AIDS. *Communication Monographs*, *67*(1), 63–84. https://doi.org/1.1080/03637750009376495

Briggs, L. A., Kirchhoff, K. T., Hammes, B. J., Song, M. K., & Colvin, E. R. (2004). Patient-centered advance care planning in special patient populations: a pilot study. *Journal of Professional Nursing*, *20*(1), 47-58.

Brown, A. J., Shen, M. J., Urbauer, D., Taylor, J., Parker, P. A., Carmack, C., ... & Bodurka, D. C. (2017). The advance care planning readiness scale: Development and validation of a measure of willingness to discuss and acceptance of end-of-life care in gynecologic cancer patients. *International Journal of Gynecologic Cancer*, *27*(4).

Burke, B. L., Martens, A., & Faucher, E. H. (2010). Two decades of terror management theory: A meta-analysis of mortality salience research. *Personality and Social Psychology Review*, *14*(2), 155-195.

Burnham, K. P., & Anderson, D. R. (2004). Multimodel inference: understanding AIC and

BIC in model selection. *Sociological methods & research*, *33*(2), 261-304.

Buttorff, C., Ruder, T., & Bauman, M. (2017). *Multiple chronic conditions in the United States* (Vol. 10). Santa Monica, CA: Rand.

Byrne, B. M. (2013). *Structural equation modeling with Mplus: Basic concepts, applications, and programming*. Routledge.

Calvin, A. O. (2004). Hemodialysis patients and end-of-life decisions: a theory of personal preservation. Journal of advanced nursing, 46(5), 558-566.

Calvin, A. O., & Eriksen, L. R. (2006). Assessing advance care planning readiness in individuals with kidney failure. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*. *33*(2).

Calvin, A. O. (n.d.). *ACPRI Instrument*.

Campbell, M.J., Edwards, M.J., Ward, K.S., et al. (2007). Developing a parsimonious model for predicting completion of advance directives. *Journal of Nursing Scholarship*, 39, 165–171.

Carroll, P. J. (2010). Preparedness. In R. M. Arkin, K. C. Oleson, & P. J. Carroll (Eds.), *Handbook of the uncertain self* (pp. 266–290). Psychology Press.

Center for Medicare & Medicaid Services. (2021). National Health Expenditure Data: Historical. Accessed May 5, 2022. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical

Chan, R., & Webster, J. (2009). End-of-life care pathways for improving outcomes in caring for the dying. In R. Chan (Ed.), *Cochrane Database of Systematic Reviews*. John Wiley

& Sons, Ltd. https://doi.org/1.1002/14651858.cd008006

Chan, T. H., Chan, F. M., Tin, A. F., Chow, A. Y., & Chan, C. L. (2007). Death preparation and anxiety: A survey in Hong Kong. *OMEGA-Journal of Death and Dying*, *54*(1), 67-78.

Chan, H. Y., & Pang, S. M. (2010). Let me talk–an advance care planning programme for frail nursing home residents. *Journal of clinical nursing*, *19*(21-22), 3073-3084.

Chan, W., Tin, A., & Wong, K. (2015). Coping with Existential and Emotional Challenges: Development and Validation of the Self-Competence in Death Work Scale. *Journal of Pain and Symptom Management*, *50*(1), 99–107. https://doi.org/1.1016/j.jpainsymman.2015.02.012

Chang, L. (1994). A psychometric evaluation of 4-point and 6-point Likert-type scales in relation to reliability and validity. Applied psychological measurement, 18(3), 205-215.

Chen, C. H., Chen, J. S., Wen, F. H., Chang, W. C., Chou, W. C., Hsieh, C. H., Hou, M. M., & Tang, S. T. (2019). An Individualized, Interactive Intervention Promotes Terminally Ill Cancer Patients’ Prognostic Awareness and Reduces Cardiopulmonary Resuscitation Received in the Last Month of Life: Secondary Analysis of a Randomized Clinical Trial. *Journal of Pain and Symptom Management*, *57*(4), 705-714.e7. https://doi.org/1.1016/j.jpainsymman.2019.01.002

Choi, S., McDonough, I. M., Kim, M., & Kim, G. (2020). The association between the number of chronic health conditions and advance care planning varies by race/ethnicity. *Aging & mental health*, *24*(3), 453-463.

Cicirelli, V. G. (2002). Fear of death in older adults: Predictions from terror management theory. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *57*(4), P358-P366.

Clark, M. A., Person, S. D., Gosline, A., Gawande, A. A., & Block, S. D. (2018). Racial and ethnic differences in advance care planning: results of a statewide population-based survey. *Journal of palliative medicine*, *21*(8), 1078-1085.

Clayton, J. M., Butow, P. N., & Tattersall, M. H. N. (2005). When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *Journal of Pain and Symptom Management*, *30*(2), 132–144. https://doi.org/1.1016/j.jpainsymman.2005.02.014

Clayton, M. F., Dean, M, & Mishel, M (2018), Theories of uncertainty. In M. J. Smith & P. R. Liehr (Eds.). Middle range theory for nursing (4th ed., pp. 49-81). New York, NY: Springer.

Clayton, M. F., Mishel, M. H., & Belyea, M. (2006). Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. *Research in Nursing and Health*, *29*(1), 18–39. https://doi.org/1.1002/nur.20108

Collett, L. J., & Lester, D. (1969). The fear of death and the fear of dying. *The journal of Psychology*, *72*(2), 179-181.

Cornbleet, M. A., Campbell, P., Murray, S., Stevenson, M., & Bond, S. (2002). Patient-held records in cancer and palliative care: a randomized, prospective trial. *Palliative medicine*, *16*(3), 205-212.

Csikai, E. L. (2011). Developing the science of end-of-life and palliative care research: National Institute of Nursing Research summit. *Journal of Social Work in End-Of-Life*

& Palliative Care, *7*(4), 291-299.

Cubanski, J., Neuman, T., & Freed, M. (2019). The facts on Medicare spending and financing. Kaiser Family Foundation.

Cubanski, J., Neuman, T., Griffin, S., & Damico, A. (2016). Medicare spending at the end of life: a snapshot of beneficiaries who died in 2014 and the cost of their care.

Dattilo, T. M., Roberts, C. M., Fisher, R. S., Traino, K. A., Edwards, C. S., Pepper-Davis, M., ... & Mullins, L. L. (2021). The role of avoidance coping and illness uncertainty in the relationship between transition readiness and health anxiety. *Journal of Pediatric Nursing*, *59*, 125-130.

Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010). The impact of advance care planning on end-of-life care in elderly patients: Randomized controlled trial. *BMJ (Online)*, *340*(7751), 847. https://doi.org/1.1136/bmj.c1345

DeVellis, R. F. (2012). *Scale Development: Theory and Applications (Applied Social Research Methods).* SAGE Publications. Kindle Edition.

Dobbs, D., Emmett, C. P., Hammarth, A., & Daaleman, T. P. (2012). Religiosity and death attitudes and engagement of advance care planning among chronically ill older adults. *Research on Aging*, *34*(2), 113-130.

Donley, G. & Danis, M. (2011) Making the Case for Talking to Patients about the Costs of End-of-Life Care. *The Journal of Law, Medicine & Ethics*, 39(2), 183-193.

Doona, M. E., Haggerty, L. A., & Chase, S. K. (1997). Nursing presence: An existential exploration of the concept. *Research and Theory for Nursing Practice*, *11*(1), 3.

Douglas, R., & Brown, H. N. (2002). Patients' attitudes toward advance directives. *Journal of Nursing Scholarship*, *34*(1), 61-65.

Dunn, P. M., Tolle, S. W., Moss, A. H., & Black, J. S. (2007). The POLST paradigm: respecting the wishes of patients and families. *Annals of Long-Term Care* 15(9), 33-38.

Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., Herr, K., Rotella, J. D., & Casarett, D. J. (2015). Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the American Academy of hospice and palliative medicine and hospice and palliative nurses' association. *Journal of Pain and Symptom Management, 49*(4), 773–781. https://doi.org/1.1016/j.jpainsymman.2015.01.012

Emanuel, E. J., Fairclough, D. L., Wolfe, P., & Emanuel, L. L. (2004). Talking with terminally ill patients and their caregivers about death, dying, and bereavement: is it stressful? Is it helpful? *Archives of internal medicine*, *164*(18), 1999-2004.

Farrell, T. W., Ferrante, L. E., Brown, T., Francis, L., Widera, E., Rhodes, R., ... & Saliba, D. (2020). AGS position statement: resource allocation strategies and age-related considerations in the COVID-19 era and beyond. *Journal of the American Geriatrics Society*, *68*(6), 1136-1142.

Fawole, O. A., Dy, S. M., Wilson, R. F., Lau, B. D., Martinez, K. A., Apostol, C. C., ... & Aslakson, R. A. (2012). A Systematic Review of Communication Quality Improvement Interventions for Patients with Advanced and Serious Illness. *Journal of General Internal Medicine*. doi: 1.1007/s11606-012-2204-4

Feifel, H. (1959). The meaning of death. New York: McGraw-Hill.

Feifel, H. (1969). Attitudes toward death: A psychological perspective. *Journal of Consulting and Clinical Psychology, 33*(3), 292-295.

Field, M., & Cassel, C. (1997). *Approaching death: improving care at the EOL*. National

Academies Press.

Fisher, K., Seow, H., Cohen, J., Declercq, A., Freeman, S., & Guthrie, D. M. (2015). Patient characteristics associated with prognostic awareness: a study of a Canadian palliative care population using the InterRAI palliative care instrument. *Journal of Pain and Symptom Management*, *49*(4), 716-725.

Fleming, J., Farquhar, M., Brayne, C., Barclay, S., Buck, J., Dening, T., Hunter, S., Mukaetova-Ladinska, E., O'Sullivan, A., Paykel, E., Romero-Ortuno, R., & Zhao, J. E. (2016). Death and the oldest old: Attitudes and preferences for end-of-life care - Qualitative research within a population-based cohort study. *PLoS ONE*, *11*(4). https://doi.org/1.1371/journal.pone.0150686

Florian, V., & Har-Even, D. (1983). Fear of personal death: The effects of sex and religious belief. *Omega*, 14, 83-91.

Florian, V., & Kravetz, S. (1983). Fear of personal death: Attribution, structure, and relation to religious belief. *Journal of personality and social psychology*, *44*(3), 600-607.

Florian, V., Kravetz, S., & Frankel, J. (1984). Aspects of fear of personal death, levels of awareness, and religious commitment. *Journal of research in Personality*, *18*(3), 289-304.

Florian, V., & Mikulincer, M. (1997). Fear of death and the judgment of social transgressions: a multidimensional test of terror management theory. *Journal of personality and social psychology*, *73*(2), 369.

Florian, V., & Mikulincer, M. (2004). A multifaceted perspective on the existential meanings, manifestations, and consequences of the fear of personal death. *Handbook of experimental existential psychology*, 54-70.

Florian, V., Mikulincer, M., & Hirschberger, G. (2002). The anxiety-buffering function of close relationships: evidence that relationship commitment acts as a terror management mechanism. *Journal of personality and social psychology*, *82*(4), 527.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of health and social behavior*, 219-239.

Francke, A. L., & Willems, D. L. (2005). Terminal Patients' Awareness of Impending Death. *Cancer nursing*, *28*(3), 241-247.

Frankl, V. (1984). *Man's search for meaning: An introduction to Logotherapy*. Riverside, NJ: Simon and Schuster Adult Publishing Group.

Freeston, M. H., Rhéaume, J., Letarte, H., Dugas, M. J., & Ladouceur, R. (1994). Why do people worry? *Personality and individual differences*, *17*(6), 791-802.

Freeze, R., & Raschke, R. L. (2007). An assessment of formative and reflective constructs in IS research. *ECIS 2007 Proceedings*. 171. https://aisel.aisnet.org/ecis2007/171

Fried, T. R., Bullock, K., Iannone, L., & O'leary, J. R. (2009). Understanding advance care planning as a process of health behavior change. *Journal of the American Geriatrics Society*, *57*(9), 1547-1555.

Fried, T. R., Redding, C. A., Robbins, M. L., Paiva, A., O'Leary, J. R., & Iannone, L. (2010). Stages of change for the component behaviors of advance care planning. *Journal of the American Geriatrics Society*, 58 (12), 2329-2336.

Garrido, M. M., Balboni, T. A., Maciejewski, P. K., Bao, Y., & Prigerson, H. G. (2015). Quality of life and cost of care at the end of life: the role of advance directives. *Journal of pain and symptom management*, *49*(5), 828-835.

Gesser, G., Wong, P. T., & Reker, G. T. (1987). Death Attitudes Across the Lifespan: The

Development and Validation of the Death Attitude Profile (DAP).

Gesser, G., Wong, P., & Reker, G. (1988). Death attitudes across the lifespan: The development and validation of the Death Attitude Profile (DAP). *Omega: The Journal of Death and Dying*, 18, 113–128.

Goodman, D. C., Esty, A. R., Fisher, E. S., & Chang, C.H. (2011). Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness. In *A Report of the Dartmouth Atlas Project*. http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

Gramling, R., Stanek, S., Han, P. K., Duberstein, P., Quill, T. E., Temel, J. S., ... & Norton, S. A. (2018). Distress due to prognostic uncertainty in palliative care: frequency, distribution, and outcomes among hospitalized patients with advanced cancer. *Journal of palliative medicine*, *21*(3), 315-321.

Griffin, K. W., & Rabkin, J. G. (1998). Perceived control over illness, realistic acceptance, and psychological adjustment in people with AIDS. *Journal of Social and Clinical Psychology*, *17*(4), 407-424.

Grimaldo, D. A., Wiener-Kronish, J. P., Jurson, T., Shaughnessy, T. E., Curtis, J. R., & Liu, L. L. (2001). A randomized, controlled trial of advance care planning discussions during preoperative evaluations. *The Journal of the American Society of Anesthesiologists*, *95*(1), 43-50.

Gupta, L., Malik, A., & Singh, R. (2016). Construct of Psychological Preparedness and its Correlates. *International Journal of Indian Psychology*, *3*(2).

Gutheil, I. A., & Heyman, J. C. (2005). Communication between older people and their health care agents: results of an intervention. *Health & Social Work*, *30*(2), 107-116.

Haley, W. E., Allen, J. Y., & Kwak, J. (2011). Advance care planning and end-of-life decision making. *Annual review of gerontology and geriatrics*, *31*(1), 143-165.

Hancock, K., Clayton, J. M., Parker, S. M., Walder, S., Butow, P. N., Carrick, S., ... & Tattersall, M. H. (2007). Discrepant perceptions about end-of-life communication: a systematic review. *Journal of pain and symptom management, 34*(2), 190-200.

Hegedus, K., Zana, A., & Szabó, G. (2008). Effect of end-of-life education on medical students' and health care workers' death attitude. *Palliative Medicine, 22*(3), 264-269.

Herbert, R., Dang, Q. & Schulz, R. (2006a). Preparedness for the Death of a Loved One and Mental Health in Bereaved Caregivers of Patients with Dementia: Findings from the REACH Study. *Journal of Palliative Medicine*; 9(3) 684-691.

Herbert, R., Prigerson, C., Schulz, R., & Aronld, R. (2006b). Preparing Caregivers for the Death of a Loved One: A Theoretical Framework and Suggestions for Future Research. *Journal of Palliative Medicine*; 9(5):1164-1171.

Heyland, D. K., Barwich, D., Pichora, D., Dodek, P., Lamontagne, F., You, J. J., ... & Canadian Researchers at the End-of-Life Network (CARENET). (2013). Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA internal medicine*, *173*(9), 778-787.

Heyman, J. C., & Gutheil, I. A. (2010). Older Latinos' attitudes toward and comfort with end-of-life planning. *Health & social work, 35*(1), 17-26.

Hickman, S. E., Tolle, S. W., Brummel-Smith, K., & Carley, M. M. (2004). Use of the Physician Orders for Life-Sustaining Treatment Program in Oregon Nursing Facilities: Beyond Resuscitation Status. *Journal of the American Geriatrics Society*, 52(9), 1424-1429.

Hickman, S. E., Sabatino, C. P., Moss, A. H., & Nester, J. W. (2008). The POLST (Physician Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation. *The Journal of Law, Medicine & Ethics*, 36(1), 119-14.

Hines, S. C. (2001). Coping with uncertainties in advance care planning. *Journal of communication*, *51*(3), 498-513.

Hoelter, J. W. (1979). Multidimensional treatment of fear of death. *Journal of consulting and clinical psychology*, *47*(5), 996-999.

Hong, M., Yi, E. H., Johnson, K. J., & Adamek, M. E. (2017). Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the US: A Systematic Review of the Current Literature. *Journal of Immigrant and Minority Health*, 1-11.

Hooper, T., & Spilka, B. (1970). Some meanings and correlates of future time and death among college students. *OMEGA-Journal of Death and Dying*, *1*(1), 49-56.

Huang, C. H. S., Crowther, M., Allen, R. S., DeCoster, J., Kim, G., Azuero, C., ... & Kvale, E. (2016). A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. *Journal of palliative medicine*, *19*(2), 164-173.

Hutchison, L. A., Raffin-Bouchal, D. S., Syme, C. A., Biondo, P. D., & Simon, J. E. (2017). Readiness to participate in advance care planning: a qualitative study of renal failure patients, families, and healthcare providers. *Chronic Illness*, *13*(3), 171-187.

Institute of Medicine. (IOM). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

Institute of Medicine. (IOM). (2010). *The future of nursing: Leading change, advancing* *health.* Washington, DC: The National Academies Press. Retrieved from: http:// www.iom .edu/Reports/2010/The-Future-of- Nursing-Leading-Change-Advancing-Health.

Jabbarian, L. J., Zwakman, M., van der Heide, A., Kars, M. C., Janssen, D. J., van Delden, J. J., ... & Korfage, I. J. (2018). Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax*, *73*(3), 222-230

Johnson, R. W., Zhao, Y., Newby, L. K., Granger, C. B., & Granger, B. B. (2012). Reasons for noncompletion of advance directives in a cardiac intensive care unit. *American Journal of Critical Care*, *21*(5), 311-32.

Jones, L., Harrington, J., Barlow, C. A., Tookman, A., Drake, R., Barnes, K., & King, M. (2011). Advance care planning in advanced cancer: Can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliative and Supportive Care*, *9*(1), 3–13. https://doi.org/1.1017/S1478951510000490

Kass-Bartelmes, B. L., & Hughes, R. (2004). Advance care planning: preferences for care at the end of life. *Journal of pain & palliative care pharmacotherapy*, *18*(1), 87-109.

Kellner, R. (1986). Illness attitude scales. *Somatization and hypochondriasis*, 319-324.

Kermel-Schiffman, I., & Werner, P. (2017). Knowledge regarding advance care planning: A systematic review. *Archives of gerontology and geriatrics*, *73*, 133-142.

Khairuddin, N., Lau, S. T., Ang, W., Tan, P. H., Goh, Z., Ang, N., & Lau, Y. (2020). Implementing advance care planning: A qualitative exploration of nurses' perceived benefits and challenges. *Journal of nursing management*, *28*(5), 1080–1087. https://doi.org/1.1111/jonm.13056

Killackey, T., Peter, E., MacIver, J., & Mohammed, S. (2019). Advance care Planning in Heart Failure: A Narrative synthesis of the Perspectives of Patients, Family Members, and Healthcare Providers. *Canadian Journal of Cardiovascular Nursing*, *29*(3).

Kim, S. H., & Choi, J. (2014). Understanding of life-sustaining treatment in patients with chronic illness and their willingness to complete advance directives. *Journal of hospice & palliative nursing*, 16(4), 217-223.

Kim, B. H., Choi, J. E., Cho, J. A., Cho, J. H., & Kim, M. S. (2015). Death, Fear, and Readiness as Factors Associated with Successful Aging: Perspectives from the Lay Definitions of Older Patients. *Journal of Hospice & Palliative Nursing*, *17*(2), 149-156.

Kim, E., & Lee, K. S. (2021). Factors associated with willingness to complete advance directives in older adults. *Geriatric Nursing*, *42*(5), 1042-1047.

Kirchhoff, K. T., Hammes, B. J., Kehl, K. A., Briggs, L. A., & Brown, R. L. (2010). Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. *Journal of the American Geriatrics Society*, *58*(7), 1233-1240.

Klingler, C., In Der Schmitten, J., & Marckmann, G. (2016). Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. In *Palliative Medicine* (Vol. 30, Issue 5, pp. 423–433). https://doi.org/1.1177/0269216315601346

Klug, L., & Sinha, A. (1987). Death acceptance: A two-component formulation and scale. *OMEGA--Journal of Death and Dying*, 18(3), 229-235.

Ko, E., Lee, J., & Hong, Y. (2016). Willingness to complete advance directives among low-income older adults living in the USA. *Health & social care in the community*, *24*(6), 708-716.

Korfage, I. J., Carreras, G., Arnfeldt Christensen, C. M., Billekens, P., Bramley, L., Briggs, L., ... & Rietjens, J. A. (2020). Advance care planning in patients with advanced cancer: A 6-country, cluster-randomised clinical trial. *PLoS medicine*, *17*(11), e1003422.

Krawczyk, M., & Gallagher, R. (2016). Communicating prognostic uncertainty in potential end-of-life contexts: Experiences of family members. *BMC Palliative Care*, *15*(1). https://doi.org/1.1186/s12904-016-0133-4

Krieger, S. R., Epting, F. R. and Leitner, L. M. (1974). Personal constructs, threat, and attitudes toward death. *Omega*, *5*: 299–310.

Krumholz, H. M., Nuti, S. V., Downing, N. S., Normand, S. L. T., & Wang, Y. (2015). Mortality, hospitalizations, and expenditures for the Medicare population aged 65 years or older, 1999-2013. *Jama*, *314*(4), 355-365.

Kübler-Ross, E. (2005). *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. Simon & Schuster Ltd, New York.

Kubler-Ross, E. (1969). *On death and dying* (Vol. 1). New York: Macmillan.

Kübler-Ross, E. (1987). *AIDS: The ultimate challenge*. New York: Collier Books.

Lee, I. A., & Preacher, K. J. (2013). Calculation for the Test of the Difference between Two Dependent Correlations with One Variable in Common [Computer Software]. Retrieved from: http://quantpsy.org/corrtest/corrtest2.htm

Lehto, R. H., & Stein, K. F. (2009). Death anxiety: An analysis of an evolving concept.

Research and Theory for Nursing Practice, *23*(1), 23–41. https://doi.org/1.1891/1541-6577.23.1.23

Lehto, R., & Therrien, B. (2010). Death concerns among individuals newly diagnosed with lung cancer. *Death Studies*, *34*(10), 931–946. https://doi.org/1.1080/07481181003765477

Leong, S. M., Tam, K. I., Che, S. L., & Zhu, M. X. (2021). Prevalence and Predictors of Willingness to Make Advance Directives among Macao Chinese. *International Journal of Environmental Research and Public Health*, *18*(15), 7942.

Levi, B. H., Dellasega, C., Whitehead, M., & Green, M. J. (2010). What influences individuals to engage in advance care planning? *American Journal of Hospice and Palliative Medicine®*, *27*(5), 306-312.

Levoy, K., Tarbi, E. C., & De Santis, J. P. (2020). End-of-life decision making in the context of chronic life-limiting disease: a concept analysis and conceptual model. *Nursing Outlook*, *68*(6), 784–807. https://doi.org/1.1016/j.outlook.202.07.008

Lo, C., Hales, S., Zimmermann, C., Gagliese, L., Rydall, A., & Rodin, G. (2011). Measuring death-related anxiety in advanced cancer: Preliminary psychometrics of the death and dying distress scale. In *Journal of Pediatric Hematology/Oncology* (Vol. 33, Issue SUPPL. 2). https://doi.org/1.1097/MPH.0b013e318230e1fd

Lokker, M. E., Van Zuylen, L., Veerbeek, L., Van Der Rijt, C. C. D., & Van Der Heide, A. (2012). Awareness of dying: It needs words. *Supportive Care in Cancer*, *20*(6), 1227–1233. https://doi.org/1.1007/s00520-011-1208-7

Lum, H. D., Sudore, R. L., & Bekelman, D. B. (2015). Advance care planning in the elderly. *Medical Clinics*, *99*(2), 391-403.

Mack, J. W., Weeks, J. C., Wright, A. A., Block, S. D., & Prigerson, H. G. (2010). End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *Journal of Clinical Oncology*, 28(7), 1203-1208.

MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological methods*, *4*(1), 84.

Mack, J. W., Nilsson, M., Balboni, T., Friedlander, R. J., Block, S. D., Trice, E., & Prigerson, H. G. (2008). Peace, Equanimity, and Acceptance in the cancer experience (PEACE) Validation of a scale to assess acceptance and struggle with terminal illness. *Cancer: Interdisciplinary International Journal of the American Cancer Society*, *112*(11), 2509-2517.

Malkina-Pykh, I. G., & Pykh, Y. A. (2013). An integrated model of psychological preparedness for threat and impacts of climate change disasters. *WIT Transactions on the Built Environment*, *133,* 121-132.

McAfee, C. A., Jordan, T. R., Sheu, J. J., Dake, J. A., & Kopp Miller, B. A. (2017). Predicting racial and ethnic disparities in advance care planning using the Integrated Behavioral Model. *OMEGA – Journal of Death and Dying*, *78*(2), 335–347.

McLeod-Sordjan, R. (2013). Death preparedness: a concept analysis. *Journal of Advanced Nursing*, 00(0), doi:1.1111/jan.12252.

McLennan, J., Cowlishaw, S., Paton, D., Beatson, R., & Elliott, G. (2014). Predictors of south-eastern Australian householders' strengths of intentions to self-evacuate if a wildfire threatens: Two theoretical models. *International Journal of Wildland Fire,* 23, 1176–1188.

McMahan, R. D., Knight, S. J., Fried, T. R., & Sudore, R. L. (2013). Advance care planning beyond advance directives: Perspectives from patients and surrogates. *Journal of Pain and Symptom Management*, *46*(3), 355–365. https://doi.org/1.1016/j.jpainsymman.2012.09.006

McMordie, W. R. (1982). Concurrent validity of Templer and Templer/Mc Mordie Death Anxiety Scales. *Psychological Reports*, *51*(1), 265-266.

Meehan, E., Foley, T., Kelly, C., Kelleher, A. B., Sweeney, C., Hally, R. M., ... & Cornally, N. (2020). Advance care planning for individuals with chronic obstructive pulmonary disease: a scoping review of the literature. *Journal of pain and symptom management*, *59*(6), 1344-1361.

Merriam-Webster (Ed.). (2019). *Merriam-Webster's Online dictionary*. Merriam-Webster.

Meyers, L. S., Gamst, G., & Guarino, A. J. (2021). *Applied multivariate research: Design and interpretation*. Sage publications.

Mishel, M. H. (1988). Uncertainty in illness. *Journal of Nursing Scholarship*, 20, 225-231.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship*, 22, 256-262.

Mishel, M., Braden, C. (1987). Uncertainty: A mediator between support and adjustment. *Western Journal of Nursing Research*, 2, 43–57.

Mishel M., Braden, C. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research*, 34, 98–103.

Mishel, M. H., & Clayton, M. F. (2008). Theories of uncertainty in illness. *Middle range theory for nursing*, *3*, 53-86.

Mishel, M. H., & Fleury, J. (2001). The growth through uncertainty scale. *Unpublished Manuscript.*

Miyashita, J., Kohno, A., Cheng, S. Y., Hsu, S. H., Yamamoto, Y., Shimizu, S., ... & Fukuhara, S. (2020). Patients' preferences and factors influencing initial advance care planning discussions' timing: A cross-cultural mixed-methods study. *Palliative Medicine*, *34*(7), 906-916.

Mokkink, L. B., Prinsen, C. A., Patrick, D. L., Alonso, J., Bouter, L. M., De Vet, H. C., & Terwee, C. B. (2019). COSMIN Study Design checklist for patient-reported outcome measurement instruments. *Amsterdam, The Netherlands*, 1-32.

Morrissey, S. A., & Reser, J. P. (2003). Evaluating the effectiveness of psychological preparedness advice in community cyclone preparedness materials. *Australian Journal of Emergency Management, The*, *18*(2), 46-61.

Murphy, C. P., Sweeney, M. A., & Chiriboga, D. (2000). An educational intervention for advance directives. *Journal of Professional Nursing*, *16*(1), 21-30.

Murphy, S. L., Xu, J., Kochanek, K. D., Arias, E., & Tejada-Vera, B. (2021). Deaths: final data for 2018. In N. C. for H. S. (U. S.). D. of V. Statistics. (Ed.), *National Vital Statistics Reports*, *69(13).* https://stacks.cdc.gov/view/cdc/100479

Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N., & Walton, T. (2018). Provider tools for advance care planning and goals of care discussions: a systematic review. *American Journal of Hospice and Palliative Medicine®*, *35*(8), 1123-1132.

Nakamura, M. (2019). Readiness for advance care planning in older adults: A literature review. *Open Journal of Nursing*, *9*(01), 14.

Nardi, M., French, E., Jones, J. B., & McCauley, J. (2016). Medical spending of the US elderly. *Fiscal Studies*, *37*(3-4), 717-747.

National Academies of Medicine (2017, May 1). *EOL 2*. https://nam.edu/community-based-models-of-care-delivery-for-people-with-serious-illness/eol-2/

National Institute of Nursing Research (NINR, 2013). *Building momentum: The science of end-of-life and palliative care*. A review of research trends and funding, 1997–2010; Retrieved from: https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR-Building-Momentum-508.pdf

Neimeyer, R. A. (1994). The Threat Index and related methods.

Neimeyer, R. A., Dingemans, P. M., & Epting, F. R. (1977). Convergent validity, situational stability, and meaningfulness of the Threat Index. *OMEGA-Journal of Death and Dying*, *8*(3), 251-265.

Neimeyer, R. A., Moser, R. P., & Wittkowski, J. (2003). Assessing Attitudes Toward Dying and Death: Psychometric Considerations. In *OMEGA - Journal of Death and Dying, 47(1).* https://doi.org/1.2190/ep4r-tulm-w52g-l3ex

Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies, 28 (4),* 309-34. https://doi.org/1.1080/07481180490432324

Neimeyer, R. A. (2005). From Death Anxiety to Meaning Making at the End of Life: Recommendations for Psychological Assessment. *Clinical Psychology: Science and Practice*, *12*(3), 354–357.

Nguyen, M., Chamber-Evans, J., Joubert, A., Drouin, I., & Ouellet, I. (2013). Exploring the advance care planning needs of moderately to severely ill people with COPD. *International Journal of Palliative Nursing*, *19*(8), 389-395.

Nicholas, L., Langa, K., Iwashyna, T., & Weir, D. (2011). Regional variation in the association between advance directives and end-of-life Medicare expenditures. *Journal of American Medical Association*., 306(13), 447–453.

Nolan, M. T., & Bruder, M. (1997). Patients’ attitudes toward advance directives and end-of-life treatment decisions. *Nursing Outlook*, 45 (4). https://doi.org/1.1016/S0029-6554(97)90066-X

Österman, S., Axelsson, E., Lindefors, N., Hedman-Lagerlöf, E., Hedman-Lagerlöf, M., Kern, D., ... & Ivanov, V. Z. (2022). The 14-item short health anxiety inventory (SHAI-14) used as a screening tool: appropriate interpretation and diagnostic accuracy of the Swedish version. *BMC psychiatry*, *22*(1), 701.

Oxford English Dictionary (2017). Preparedness.

Palmer, M. K., Jacobson, M., & Enguidanos, S. (2021). Advance Care Planning for Medicare Beneficiaries Increased Substantially, But Prevalence Remained Low: Study examines Medicare outpatient advance care planning claims and prevalence. *Health Affairs*, *40*(4), 613-621.

Parse, R. R. (2010). Human dignity: A human becoming ethical phenomenon. *Nursing Science Quarterly*, *23*(3), 257-262.

Parse, R. R. (1997). The human becoming theory: The was, is, and will be. *Nursing science quarterly*, *10*(1), 32-38.

Piers, R. D., van Eechoud, I. J., Van Camp, S., Grypdonck, M., Deveugele, M., Verbeke, N. C., & Van Den Noortgate, N. J. (2013). Advance care planning in terminally ill and frail older persons. *Patient education and counseling*, *90*(3), 323-329.

Peirce, A. G. (2007). From intrusive to oscillating thoughts. *Archives of Psychiatric Nursing*, *21*(5), 278-286.

Polit, D., & Beck, C. (2020). *Essentials of nursing research: Appraising evidence for nursing practice*. Lippincott Williams & Wilkins.

Polit, D. F., & Yang, F. M. (2016). *Measurement and the measurement of change: a primer for the health professions* (Vol. 3). Philadelphia: Wolters Kluwer.

Porritt, E. (2001). Reflections on the phenomenon of readiness for death. *Australian Journal of Holistic Nursing*, *8*(2), 13-21.

Pritchard, R. S., Fisher, E. S., Teno, J. M., Sharp, S. M., Reding, D. J., Knaus, W. A., ... & Lynn, J. (1998). Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *Journal of the American Geriatrics Society,* 46(10), 1242-125.

Rains, S. A., & Tukachinsky, R. (2015). Information Seeking in Uncertainty Management Theory: Exposure to Information about Medical Uncertainty and Information-Processing Orientation as Predictors of Uncertainty Management Success. *Journal of Health Communication*, *20*(11), 1275–1286. https://doi.org/1.1080/1081073.2015.1018641

Rao, J. K., Anderson, L. A., Lin, F. C., & Laux, J. P. (2014). Completion of advance directives among US consumers. *American journal of preventive medicine*, *46*(1), 65-7.

Reed, G. M., Kemeny, M. E., Taylor, S. E., Wang, H. Y. J., & Visscher, B. R. (1994). Realistic acceptance as a predictor of decreased survival time in gay men with AIDS. *Health Psychology*, *13*(4), 299-307.

Reser, J., & Morrissey, S. (2009). The crucial role of psychological preparedness for disasters. *InPsych: The Bulletin of the Australian Psychological Society*, *31*(2), 14-15.

Richards, N., Ingleton, C., Gardiner, C., & Gott, M. (2013). Awareness contexts revisited: indeterminacy in initiating discussions at the end-of-life. *Journal of advanced nursing*, *69*(12), 2654-2664.

Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., & Korfage, I. J. (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*, 18 (9), e543-e551. Publishing Group. https://doi.org/1.1016/S1470-2045(17)30582-X

Riley, G. F., & Lubitz, J. D. (2010). Long-Term Trends in Medicare Payments in the Last Year of Life. *Health Services Research*, 45(2), 565-576.

Rocks, J. W., & Mehta, P. (2022). Memorizing without overfitting: Bias, variance, and interpolation in overparameterized models. *Physical Review Research*, *4*(1), 013201.

Routledge, C., & Juhl, J. (2010). When death thoughts lead to death fears: Mortality salience increases death anxiety for individuals who lack meaning in life. *Cognition and Emotion*, *24*(5), 848-854.

Ruff, H., Jacobs, R. J., Fernandez, M. I., Bowen, G. S., & Gerber, H. (2011). Factors associated with favorable attitudes toward end-of-life planning. *American Journal of Hospice and Palliative Medicine®*, *28*(3), 176-182.

Sabatino, C. P. (2014). Advance Care Planning Tools That Educate, Engage, and Empower. *Public Policy & Aging Report*, *24*(3), 107–111. https://doi.org/1.1093/ppar/pru018

Sakai, S., Nagae, H., Miyashita, M., Harasawa, N., Iwasaki, T., Katayama, Y., ... & Tamura, K. (2022). Developing an Instrument to Assess the Readiness for Advance Care Planning. *Journal of Pain and Symptom Management*, *63*(3), 374-386.

Salkovskis, P. M., Rimes, K. A., Warwick, H. M., & Clark, D. M. (2002). The Health Anxiety Inventory: Development and validation of scales for the measurement of health anxiety and hypochondriasis. *Psychological Medicine*, *32*, 843–853.

Sana, C. P. (2014). A Voyage to the twilight : Exploring death preparation among the elderly. *Philippine Journal of Nursing*, 84. 14-23.

Sánchez-Fernández, J., Muñoz-Leiva, F., & Montoro-Ríos, F. J. (2012). Improving retention rate and response quality in Web-based surveys. *Computers in Human Behavior*, *28*(2), 507-514.

Sanders, J. J., Johnson, K. S., Cannady, K., Paladino, J., Ford, D. W., Block, S. D., & Sterba, K. R. (2019). From barriers to assets: Rethinking factors impacting advance care planning for African Americans. *Palliative and Supportive Care*, *17*(3), 306–313. https://doi.org/1.1017/S147895151800038X

Sanders, J. J., Robinson, M. T., & Block, S. D. (2016). Factors impacting advance care planning among African Americans: results of a systematic integrated review. *Journal of palliative medicine*, *19*(2), 202-227.

Saunders, C. (1959). Should a patient know…? Nursing Times. 994-995.

Saunders, C. (1978). The management of terminal disease.

Saunders, C. (1993). The management of terminal malignant disease.

Schickedanz, A. D., Schillinger, D., Landefeld, C. S., Knight, S. J., Williams, B. A., & Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *Journal of the American Geriatrics Society*, *57*(1), 31-39.

Schumacker, R. E., and Lomax, R. G. (2004). A beginner's guide to structural equation Modeling. Second edition. Mahwah, NJ: Lawrence Erlbaum Associates

Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: issues and guidelines for family physicians. *American family physician*, *71*(3), 515-522.

Sharkey, C. M., Perez, M. N., Bakula, D. M., Grant, D. M., & Mullins, L. L. (2019). Exploratory factor analysis of the mishel uncertainty in illness scale among adolescents and young adults with chronic medical conditions. *Journal of Pediatric Health Care*, *33*(2), 186-194.

Siegert, E. A., Clipp, E. C., Mulhausen, P., & Kochersberger, G. (1996). Impact of advance directive videotape on patient comprehension and treatment preferences. *Archives of family medicine*, *5*(4), 207.

Silveira, M. J., Kim, S. Y. H., & Langa, K. M. (2010). Advance Directives and Outcomes of Surrogate Decision Making Before Death. *Survey of Anesthesiology, 54(5).* https://doi.org/1.1097/sa.0b013e3181f21fb0

Silveira, M. J., Wiitala, W., & Piette, J. (2014). Advance directive completion by elderly Americans: a decade of change. *Journal of the American Geriatrics Society*, *62*(4), 706-71.

Sinclair, C., Auret, K. A., Evans, S. F., Williamson, F., Dormer, S., Wilkinson, A., ... & Brims, F. (2017). Advance care planning uptake among patients with severe lung disease: a randomised patient preference trial of a nurse-led, facilitated advance care planning intervention. *BMJ open*, *7*(2), e013415.

Skulason, B., Hauksdottir, A., Ahcic, K., & Helgason, A. R. (2014). Death talk: gender differences in talking about one's own impending death. *BMC Palliative Care*, *13*(1), 1-11.

Song, M. K., Kirchhoff, K. T., Douglas, J., Ward, S., & Hammes, B. (2005). A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. *Medical care*, 1049-1053.

Song, M. K., & Sereika, S. M. (2006). An evaluation of the Decisional Conflict Scale for measuring the quality of end-of-life decision making. *Patient Education and Counseling*, *61*(3), 397–404. https://doi.org/1.1016/j.pec.2005.05.003

Song, M. K., Ward, S. E., Fine, J. P., Hanson, L. C., Lin, F. C., Hladik, G. A., ... & Bridgman, J. C. (2015). Advance care planning and end-of-life decision making in dialysis: a randomized controlled trial targeting patients and their surrogates. *American Journal of Kidney Diseases*, *66*(5), 813-822.

Soper, D.S. (2022). A-priori Sample Size Calculator for Structural Equation Models [Software]. https://www.danielsoper.com/statcalc

Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. *Journal of the American Geriatrics Society*, *57*(1), 31–39. https://doi.org/1.1111/j.1532-5415.2008.02093.x

Sudore, R. L., Boscardin, J., Feuz, M. A., McMahan, R. D., Katen, M. T., & Barnes, D. E. (2017). Effect of the prepare website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans a randomized clinical trial. *JAMA Internal Medicine*, *177*(8), 1102–1109. https://doi.org/1.1001/jamainternmed.2017.1607

Sudore, R. L., & Fried, T. R. (2010). Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Annals of Internal Medicine,* 153(4), 256-261.

Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A., Korfage, I. J., Ritchie, C. S., ... & You, J. J. (2018). Outcomes that define successful advance care planning: a Delphi panel consensus. *Journal of pain and symptom management*, *55*(2), 245-255.

Sudore, R., Le, G. M., McMahan, R., Feuz, M., Katen, M., & Barnes, D. E. (2015). The advance care planning PREPARE study among older Veterans with serious and chronic illness: study protocol for a randomized controlled trial. *Trials, 16*, 57. doi:1.1186/s13063-015-1055-9

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., & Heyland, D. K. (2017). Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. *Journal of Pain and Symptom Management*, *53*(5), 821-832. https://doi.org/1.1016/j.jpainsymman.2016.12.331

Sudore, R. L., Schickedanz, A. D., Landefeld, C. S., Williams, B. A., Lindquist, K., Pantilat, S. Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: a descriptive study of diverse older adults. Journal of the American Geriatrics Society, 56(6), 1006-1013.

Sudore, R. L., Stewart, A. L., Knight, S. J., McMahan, R. D., Feuz, M., Miao, Y., & Barnes, D. E. (2013). Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. *PloS One*, 8(9), 1-7.

Sun, A., Bui, Q., Tsoh, J. Y., Gildengorin, G., Chan, J., Cheng, J., ... & Nguyen, T. (2017). Efficacy of a church-based, culturally tailored program to promote completion of advance directives among Asian Americans. *Journal of immigrant and minority health*, *19*(2), 381-391.

Taneja, R., Faden, L. Y., Schulz, V., Rawal, A., Miller, K., Bishop, K. A., & Lingard, L. (2019). Advance care planning in community dwellers: a constructivist grounded theory study of values, preferences, and conflicts. *Palliative Medicine*, *33*(1), 66-73.

Tang, S. T., Chou, W. C., Chang, W. C., Chen, J. S., Hsieh, C. H., Wen, F. H., & Chung, S. C. (2019). Courses of Change in Good Emotional Preparedness for Death and Accurate Prognostic Awareness and Their Associations with Psychological Distress and Quality of Life in Terminally Ill Cancer Patients' Last Year of Life. *Journal of Pain and Symptom Management*, *58*(4), 623-631. https://doi.org/1.1016/j.jpainsymman.2019.06.022

Templer, D. I. (1970). The construction and validation of a death anxiety scale. *The Journal of general psychology*, *82*(2), 165-177.

Templer, D. I., Lavoie, M., Chalgujian, H., & Thomas-Dobson, S. (1990). The measurement of death depression. *Journal of Clinical Psychology*, *46*(6), 834-839.

Teno, J. M., Gozalo, P. L., Bynum, J. P., Leland, N. E., Miller, S. C., Morden, N. E., ... & Mor, V. (2013). Change in End-of-Life Care for Medicare Beneficiaries Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009 End-of-Life Care for Medicare Beneficiaries. *JAMA*: *the Journal of the American Medical Association*, 309(5), 470-477.

Terwee, C. B., Prinsen, C. A., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., ... & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Quality of Life Research*, *27*, 1159-1170.

Todaro-Franceschi, V. (2013). Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life. *Dimensions of Critical Care Nursing*, *32*(4), 184-190.

Tomer, A., Eliason, G. T., & Wong, P. T. (Eds.). (2007). *Existential and spiritual issues in death attitudes*. Psychology Press.

Tong, E., Deckert, A., Gani, N., Nissim, R., Rydall, A., Hales, S., ... & Lo, C. (2016). The meaning of self-reported death anxiety in advanced cancer. *Palliative medicine*, *30*(8), 772-779.

Tripken, J. L., Elrod, C., & Bills, S. (2018). Factors influencing advance care planning among older adults in two socioeconomically diverse living communities. *American Journal of Hospice and Palliative Medicine®*, *35*(1), 69-74.

Tsai, W. T., Chen, C. M., Chung, M. C., Tsai, P. Y., Liu, Y. T., Tang, F. C., & Lin, Y. L. (2022). Important factors influencing willingness to participate in advance care planning among outpatients: a pilot study in central Taiwan. *International Journal of Environmental Research and Public Health*, *19*(9), 5266.

Tulsky, J. A., Beach, M. C., Butow, P. N., Hickman, S. E., Mack, J. W., Morrison, R. S., Street, R. L., Sudore, R. L., White, D. B., & Pollak, K. I. (2017). A research agenda for communication between health care professionals and patients living with serious illness. In *JAMA Internal Medicine, 177(9),* 1361–1366.

Uitdehaag, M. J., van der Velden, L. A., de Boer, M. F., Spaander, M. C., Steyerberg, E. W., Kuipers, E. J., ... & Pruijn, J. F. (2012). Recordings of consultations are beneficial in the transition from curative to palliative cancer care: a pilot-study in patients with oesophageal or head and neck cancer. *European Journal of Oncology Nursing*, *16*(2), 109-114.

Vail III, K. E., Juhl, J., Arndt, J., Vess, M., Routledge, C., & Rutjens, B. T. (2012). When death is good for life: Considering the positive trajectories of terror management. *Personality and social psychology review*, *16*(4), 303-329.

Vaillot, Sister M. C. (1966). Existentialism: A philosophy of commitment. American Journal of Nursing, 66, 500-505.

Van Camp, S., Piers, R., van Eechoud, I., Grypdonck, M., Deveugele, M., Verbeke, N., & Van Den Noortgate, N. (2011). Advance care planning in terminally ill and frail older persons: acceptance of dying and balancing experiences, trust, and control. In *12th Congress of the European Association for Palliative Care (EAPC)*.

Verduzco-Aguirre, H. C., Babu, D., Mohile, S. G., Bautista, J., Xu, H., Culakova, E., ... & Loh, K. P. (2021). Associations of uncertainty with psychological health and quality of life in older adults with advanced cancer. *Journal of pain and symptom management*, *61*(2), 369-376.

Volandes, A. E., Ariza, M., Abbo, E. D., & Paasche-Orlow, M. (2008). Overcoming educational barriers for advance care planning in Latinos with video images. *Journal of palliative medicine*, *11*(5), 700-706.

Von Blanckenburg, P., Leppin, N., Nagelschmidt, K., Seifart, C., & Rief, W. (2021). Matters of Life and Death: An Experimental Study Investigating Psychological Interventions to

Encourage the Readiness for End-of-Life Conversations. *Psychotherapy and Psychosomatics*, *90*(4), 243–254. https://doi.org/1.1159/000511199

Vrieze, S. I. (2012). Model selection and psychological theory: A discussion of the differences between the Akaike information criterion (AIC) and the Bayesian information criterion (BIC). *Psychological Methods*, *17*(2), 228–243. https://doi.org/10.1037/a0027127

Walczak, A., Butow, P. N., Bu, S., & Clayton, J. M. (2016). A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured, and do they work? *Patient Education and Counseling, 99 (1)*, 3–16.

Walczak, A., Butow, P. N., Clayton, J. M., Tattersall, M. H. N., Davidson, P. M., Young, J., & Epstein, R. M. (2014). Discussing prognosis and end-of-life care in the final year of life: A randomized controlled trial of a nurse-led ommunication support programme for patients and caregivers. *BMJ Open*, *4*(6). https://doi.org/1.1136/bmjopen-2014-005745

Walczak, A., Butow, P. N., Davidson, P. M., Bellemore, F. A., Tattersall, M. H. N., Clayton, J. M., Young, J., Mazer, B., Ladwig, S., & Epstein, R. M. (2013). Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised? *Patient Education and Counseling*, *90*(3), 307–314. https://doi.org/1.1016/j.pec.2011.08.009

Wang, X., & Sheng, Y. (2022). Readiness for advance care planning and its relationship to coping style in patients with chronic diseases in communities: A cross-sectional study. *Nursing Open*, *9*(2), 1332-1342.

Weissman, G. E., Kerlin, M. P., Yuan, Y., Kohn, R., Anesi, G. L., Groeneveld, P. W., ... & Halpern, S. D. (2020). Potentially preventable intensive care unit admissions in the

United States, 2006–2015. *Annals of the American Thoracic Society, 17*(1), 81-88.

Wen, F. H., Chou, W. C., Chen, J. S., Chang, W. C., Hsu, M. H., & Tang, S. T. (2022). Sufficient Death Preparedness Correlates to Better Mental Health, Quality of Life, and EOL Care. *Journal of Pain and Symptom Management*, *63*(6), 988-996.

Wennberg, J. E., Fisher, E. S., Goodman, D. C., & Skinner, J. S. (2008). Tracking the Care of Patients with Severe Chronic Illness-*The Dartmouth Atlas of Health Care 2008*.

Wentlandt, K., Burman, D., Swami, N., Hales, S., Rydall, A., Rodin, G., Lo, C., & Zimmermann, C. (2012). Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers. *Psycho-Oncology*, *21*(8), 868–876. https://doi.org/1.1002/pon.1995

Winzelberg, G. S., Hanson, L. C., & Tulsky, J. A. (2005). Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, *53*(6), 1046-105.

Wittkowski, J. (2001). The construction of the multidimensional orientation toward dying and death inventory (MODDI-F). *Death Studies*, 25(6), 479-495.

Wong, P. T. (2008). Meaning management theory and death acceptance. *Existential & spiritual issues in death attitudes*, 65-88.

Wong, P. T. (2011). Meaning Making and Death Acceptance. *International Journal of Existential Psychology and Psychotherapy*, 3(2).

Wong, P. T., & Tomer, A. (2011). Beyond terror and denial: The positive psychology of death acceptance. *Death Studies*, 35(2), 99-106.

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson, V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008).

Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. In *JAMA - Journal of the American Medical Association*, *300 (14).* https://doi.org/1.1001/jama.30.14.1665

Wu, P., Lorenz, K. A., & Chodosh, J. (2008). Advance care planning among the oldest old. *Journal of palliative medicine*, *11*(2), 152-157.

Yadav, K. N., Gabler, N. B., Cooney, E., Kent, S., Kim, J., Herbst, N., ... & Courtright, K. R. (2017). Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs*, *36*(7), 1244-1251.

Yanez, N. D., Weiss, N. S., Romand, J. A., & Treggiari, M. M. (2020). COVID-19 mortality risk for older men and women. *BMC Public Health*, *20*(1), 1-7.

Yonashiro-Cho, J., Cote, S., & Enguidanos, S. (2016). Knowledge about and perceptions of advance care planning and communication of Chinese American older adults. *Journal of the American Geriatrics Society*, *64*(9), 1884-1889.

Young, Y., Stone, A., & Perre, T. (2022). Are Young Adults Ready to Complete Advance Directives? *American Journal of Hospice and Palliative Medicine®*, *39*(10), 1188-1193.

Zhang, B., Wright, A. A., Huskamp, H. A., Nilsson, M. E., Maciejewski, M. L., Earle, C. C., ... & Prigerson, H. G. (2009). Health care costs in the last week of life: associations with end-of-life conversations. *Archives of internal medicine*, *169*(5), 480-488.

Zulch, H. (2019). Psychological preparedness for natural hazards–improving disaster preparedness policy and practice. *United Nations Off Disaster Risk Reduct*, 1-43.

Zwakman, M., Jabbarian, L. J., van Delden, J. J., van der Heide, A., Korfage, I. J., Pollock, K., ... & Kars, M. C. (2018). Advance care planning: a systematic review about experiences of patients with a life-threatening or life-limiting illness. *Palliative Medicine*, *32*(8), 1305-1321.

Zwakman, M., van Delden, J. J., Caswell, G., Deliens, L., Ingravallo, F., Jabbarian, L. J., ... & Kars, M. C. (2020). Content analysis of Advance Directives completed by patients with advanced cancer as part of an Advance Care Planning intervention: insights gained from the ACTION trial. *Supportive care in cancer*, *28*, 1513-1522.

Zwakman, M., Milota, M. M., van der Heide, A., Jabbarian, L. J., Korfage, I. J., Rietjens, J. A. C., ... & Kars, M. C. (2021). Unraveling patients' readiness in advance care planning conversations: a qualitative study as part of the ACTION study. *Supportive Care in Cancer*, *29*(6), 2917-2929.

Table A 1

Psychometrics Examined and the Indicators

Psychometrics	**Indicators**
Content validity	Content Validity Index and qualitative feedback
Construct validity	
Structural validity	Exploratory and Confirmatory Factor Analysis
Hypothesis testing	See more details in the “hypotheses to be tested” section
Criterion validity	The criterion will be the self-reported behavioral outcomes of ACP (such as signed advance directive, living will, health care proxy, etc.)
Internal Consistency	Cronbach’s alpha
Test-re-test reliability	Intra-Class Coefficient

Table A 2

Instrument Combination for Each Phase of Testing

Testing Phase	**Sample Number**	**Questionnaire Included**	**Time of Administration**
Content validity	20	Demographic sheet (24 items, Appendix C), the developedadvance planning Preparedness Scale (APPS, about 50 items, Appendix A),	Week 1
Pilot Testing	30	Demographic sheet, the revised APPS, (about 40-50 items),advance care planning Readiness Instrument (ACPRI, 30 items, Appendix D), the Mishel Uncertainty in Illness Scale (MUIS-C, 23 items, Appendix E), the PEACE Questionnaire (12 items, Appendix F), the short health anxiety inventory (SHAI, 18 items, Appendix G), the Socially Desirable Response Set 5-Item Survey (SDRS-5, Appendix H) and the Pilot test Questionnaire (17 items, Appendix J)	Week 3
Full Scale	400	Demographic sheet, revised APPS, about (35-40 items), ACPRI, (30 items), the Mishel MUIS-C, 23 items, the PEACE Questionnaire (12 items), the SHAI, (18 items,), the Socially Desirable Response Set 5-Item Survey	Week 5 until sample met
Test-re-test reliability	225	Demographic sheet, revised APPS, about (35-40 items), the Socially Desirable Response Set 5-Item Survey	48-96 hours after full scale until sample met

APPENDIX A Advance Planning Preparedness Scale (Initial)

Psychological comfort with advance care planning

I would feel uneasy if someone talked to me about end-of-life planning
I feel comfortable thinking about healthcare topics related to end-of-life.
I find it comfortable to talk about end-of-life related health care.
I feel comfortable discussing the risks and benefits of limiting medical care at end of life.
I feel prepared to discuss who should make medical decisions for me if I am unable to.
I feel comfortable talking about planning for health care related to end of life.
I feel prepared making decisions about end-of-life related health care ahead of time
I would feel uneasy to talking about a terminal medical condition with my healthcare provider
I prefer to make an Advance Directive when I am healthy
I feel comfortable with talking about my feelings about getting sicker
I feel comfortable talking about how long I have to live
I feel ease with being asked about the things that are important to me
I am comfortable with discussing my feelings about my wishes at end of life
I feel comfortable discussing my emotions regarding a decline in my health
I feel comfortable discussing my health care choices at end of life

Knowledge (The Desire to Know)

I prefer to discuss advance care planning when I first get diagnosed with a serious illness.
I desire knowledge related to the term advance care planning
I need to know about advance directives
I want to know the choices about the treatment at the end of my life
I know the nature of the medical problems I have
I desire facts about advance care planning can help me to get the treatment what I want when I am no longer able to make my own decisions
I prefer to discuss treatments that will avoid CPR at end of life
I want to know if I have an illness that is life threatening
I do not want to know about a condition that will cause imminent death
I prefer to have treatments that honor limiting intensive care treatments
I need knowledge about illnesses that are life threatening
I do not want to have knowledge about a condition that will cause my death
I prefer to have the true facts about whether my illness is terminal
I know what an advanced directive is
I want to be aware of the possibility that I may lose the ability to make my own medical decisions if I become seriously ill or injured

Thinking

I don’t want to think about end-of-life discussions
I have thought about issues related to the quantity versus the quality of life
I have thought about the pros and cons of having an advanced directive
I have thought about my medical illnesses getting worse
I have thought about what I would want when I get really sick
I have thought about my medical illnesses getting worse
I have thought about what I would want when I get really sick
I have thoughts that my illness will not get better

I think about having an advance directive
I think about the things I still want to do in this life.
I think about my preferences for treating my illnesses in the future.
I have thoughts about people I value
I think about my values I want to maintain at the end of life

Willingness
I am not willing to engage in advance care planning
I am willing to express my wishes in advance about limiting intensive care treatments
I am willing to go along with a request to discuss my end of life wishes
I am not willing to talk about health care issues related to end of life
I am willing to talk about my illness with family members that are important to me
I am willing to talk about my end of life with my doctors and nurses
Existential Reflection
I have an illness that is life threatening
I do not have a condition that will cause my death
I want to focus on the meaning of life when I approach to the end of life.
I can imagine a scenario where my illness or other incidents will cause my death
I am peaceful when reflecting about the end of my life
I am satisfied with the meaning I have given to my life

APPENDIX B Content Validity Form Advance Planning Preparedness Scale

The scale items that follow have been developed to measure the construct of preparedness for advance care planning. Please read each domain and definition. Please read each item and score it for its relevance in representing the domain defined. There are five domains; Psychological comfort with advance care planning, Knowledge, Thinking, Willingness and Existential Reflection.

Domain 1: Psychological comfort with advance care planning *Definition: Psychologically and emotionally feeling at ease with advance care planning*	***Item Relevance Rating***			
	Not Relevant	***Somewhat Relevant***	***Quite Relevant***	***Highly Relevant***
PC1. I would feel uneasy if someone talked to me about end-of-life planning				
PC2.I feel comfortable thinking about healthcare topics related to end of life				
PC3. I find it comfortable to talk about end-of-life related health care.				
PC4. I feel comfortable discussing the risks and benefits of limiting medical care at end of life.				
PC5. I feel prepared to discuss who should make medical decisions for me if I am unable to.				
PC6.I feel comfortable talking about planning for health care related to end of life				
PC7.I feel prepared making decisions about end-of-life related health care ahead of time.				
PC8.I would feel uneasy to talking about a terminal medical condition with my healthcare provider				
PC9.I prefer to make an Advance Directive when I am healthy				
PC1. I feel comfortable with talking about my feelings about getting sicker				
PC11.I feel comfortable talking about how long I have to live				

PC12.I feel ease with being asked about the things that are important to me				
PC13.I feel comfortable discussing my health care choices at end of life				
PC14.I feel comfortable discussing my emotions regarding a decline in my health				
PC15.I am comfortable with discussing my feelings about my wishes at end of life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not relevant to the concept of psychological comfort with advance care planning within the construct of preparedness for advance care planning.

Comment/Suggestions
PC1
PC2
PC3
PC4
PC5
PC6
PC7
PC8
PC9
PC10
PC11
PC12
PC13
PC14
PC15

Please suggest any additional items you feel would improve the measurement of ***psychological comfort with advance care planning*** or make any further comments to help improve this subscale

Domain 2: Knowledge- Desire to Know Definition: The cognitive desire to have facts related to illness and advance care planning	***Item Relevance Rating***			
	Not Relevant	***Somewhat Relevant***	***Quite Relevant***	***Highly Relevant***

K1. I prefer to discuss advance care planning when I first get diagnosed with a serious illness				
K2. I desire knowledge related to the term advance care planning				
K3. I need to know about advance directives				
K4. I want to know the choices about the treatment at the end of my life				
K5. I know the nature of the medical problems I have				
K6. I desire facts about advance care planning to help me to get the treatment I want when I am no longer able to make my own decisions				
K7. Choosing medical treatments in advance could help avoid unwanted treatments at the end of my life				
K8. I want to know if I have an illness that is life threatening				
K9, I do not want to know about a condition that will cause imminent death				
K1. Having an Advance Directive would make sure that I get the treatment I want at end of life				
K11. I need knowledge about illnesses that are life threatening				
K12. I do not want to have knowledge about a condition that will cause my death				
K13. People in good health do not need to have facts about advance care planning				
K14. I want to know what an advanced directive is				
K15. I want to be aware of the possibility that I may lose the ability to make my own medical decisions if I become seriously ill or injured				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not relevant to the concept of Knowledge within the construct of preparedness for advance care planning.

Comments/Suggestions

K1

K2
K3
K4
K5
K6
K7
K8
K9
K10
K11
K12
K13
K14
K15

Please suggest any additional items you feel would improve the measurement of ***Knowledge*** or make any further comments to help improve this subscale

Domain 3: Thinking Definition: Thoughts about ACP related issues (e.g., current health status, life goals, values, and preferences for future medical care decisions, etc.)	***Item Relevance Rating***			
	Not Relevant	***Somewhat Relevant***	***Quite Relevant***	***Highly Relevant***
T1. I don't want to think about end-of-life discussions				
T2. I have thought about issues related to the quantity versus the quality of life				
T3. I have thought about the pros and cons of having an advanced directive				
T4. I have thought about my medical illnesses getting worse				
T5. I have thought about what I would want when I get really sick				
T6. I have thoughts that my illness will not get better				
T7. I think about having an advanced directive				
T8. I think about the things I still want to do in this life				

T9. I think about my preferences for treating my illness in the future				
T1. I have thoughts about people I value				
T11. I think about my values that I want to maintain at the end of life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not relevant to the concept of Thinking within the construct of preparedness for advance care planning.

Comment/Suggestions
T1
T2
T3
T4
T5
T6
T7
T8
T9
T10
T11

Please suggest any additional items you feel would improve the measurement of **Thinking** or make any further comments to help improve this subscale

Domain 4: Willingness Definition: The readiness to participate in advance care planning	***Item Relevance Rating***			
	Not Relevant	***Somewhat Relevant***	***Quite Relevant***	***Highly Relevant***
W1. I am not willing to engage in advance care planning				

W2. I am willing to express my wishes in advance about limiting intensive care treatments				
W3. I am willing to go along with a request to discuss my end of life wishes				
W4. I am not willing to talk about health care issues related to end of life				
W5. I am willing to talk about my illness with family members that are important to me				
W6. I am willing to talk about my end of life with my doctors and nurses				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not relevant to the concept of Willingness within the construct of preparedness for advance care planning.

Comments/Suggestions
W1
W2
W3
W4
W5
W6

Please suggest any additional items you feel would improve the measurement of **Willingness** or make any further comments to help improve this subscale

Domain 5: Existential Reflection	***Item Relevance Rating***			
Definition: The individual's psyche thoughtful reflection on one's mortality, meaning of life, assumptions about life, death, and quantity vs. quality of life while exploring EOL decisions.	***Not Relevant***	***Somewhat Relevant***	***Quite Relevant***	***Highly Relevant***

E1. I have an illness that is life threatening				
E2. I do not have a condition that will cause my death				
E3. I want to focus on the meaning of life when I approach to the end of life				
E4. I can imagine a scenario where my illness or other incidents will cause my death				
E5. I am peaceful when reflecting about the end of my life.				
E6. I am satisfied with the meaning I have given to my life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not relevant to the concept of *Existential Reflection* **within the construct of preparedness for advance care planning.**

Comments/Suggestions
ER1
ER2
ER3
ER4
ER5
ER6

Please suggest any additional items you feel would improve the measurement of **Existential Reflection** or make any further comments to help improve this subscale

The scale items that follow have been developed to measure the construct of preparedness for advance care planning. Please read each domain and definition. Please read each item and score it for its Clarity. There are five domains; Psychological comfort with advance care planning, Knowledge, Thinking, Willingness and Existential Reflection.

Domain 1: Psychological comfort with advance care planning	***Item Clarity Rating***

Definition: Psychologically and emotionally feeling at ease with advance care planning	***(1) Not Clear***	***(2) Somewhat Clear***	***(3) Quite Clear***	***(4) Highly Clear***
PC1. I would feel uneasy if someone talked to me about end-of-life planning				
PC2.I feel comfortable thinking about healthcare topics related to end of life				
PC3. I find it comfortable to talk about end-of-life related health care.				
PC4. I feel comfortable discussing the risks and benefits of limiting medical care at end of life.				
PC5. I feel prepared to discuss who should make medical decisions for me if I am unable to.				
PC6.I feel comfortable talking about planning for health care related to end of life				
PC7.I feel prepared making decisions about end-of-life related health care ahead of time.				
PC8.I would feel uneasy to talking about a terminal medical condition with my healthcare provider				
PC9.I prefer to make an Advance Directive when I am healthy				
PC1. I feel comfortable with talking about my feelings about getting sicker				
PC11.I feel comfortable talking about how long I have to live				
PC12.I feel ease with being asked about the things that are important to me				
PC13.I feel comfortable discussing my health care choices at end of life				
PC14.I feel comfortable discussing my emotions regarding a decline in my health				
PC15.I am comfortable with discussing my feelings about my wishes at end of life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not clear and representative of the concept of psychological comfort *with advance care planning within the construct of preparedness for advance care planning.*

Comment/Suggestions
PC1
PC2
PC3
PC4
PC5
PC6
PC7
PC8
PC9
PC10
PC11
PC12
PC13
PC14
PC15

Please suggest any additional items you feel would improve the measurement of ***psychological comfort with advance care planning*** or make any further comments to help improve this subscale

Domain 2: Knowledge Definition: The cognitive desire to have facts related to illness and advance care planning	***Item Clarity Rating***			
	(1) Not Clear	***(2) Somewhat Clear***	***(3) Quite Clear***	***(4) Highly Clear***
K1. I prefer to discuss advance care planning when I first get diagnosed with a serious illness				
K2. I desire knowledge related to the term advance care planning				
K3. I need to know about advance directives				

K4. I want to know the choices about the treatment at the end of my life"				
K5. I know the nature of the medical problems I have				
K6. I desire facts about advance care planning to help me to get the treatment I want when I am no longer able to make my own decisions				
K7. Choosing medical treatments in advance could help avoid unwanted treatments at the end of my life				
K8. I want to know if I have an illness that is life threatening				
K9, I do not want to know about a condition that will cause imminent death				
K1. Having an Advance Directive would make sure that I get the treatment I want at end of life				
K11. I need knowledge about illnesses that are life threatening				
K12. I do not want to have knowledge about a condition that will cause my death				
K13. People in good health do not need to have facts about advance care planning				
K14. I want to know what an advanced directive is				
K15. I want to be aware of the possibility that I may lose the ability to make my own medical decisions if I become seriously ill or injured				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not clear and representative of the concept of Knowledge within the construct of preparedness for advance care planning.

Comments/Suggestions
K1
K2
K3
K4
K5
K6
K7
K8
K9
K10
K11
K12
K13
K14
K15

Please suggest any additional items you feel would improve the measurement of ***Knowledge*** or make any further comments to help improve this subscale

Domain 3: Thinking Definition: Thoughts about ACP related issues (e.g., current health status, life goals, values, and preferences for future medical care decisions, etc.)	***Item Clarity Rating***			
	(1) Not Clear	***(2) Somewhat Clear***	***(3) Quite Clear***	***(4) Highly Clear***
T1. I don't want to think about end-of-life discussions				
T2. I have thought about issues related to the quantity versus the quality of life				
T3. I have thought about the pros and cons of having an advanced directive				
T4. I have thought about my medical illnesses getting worse				
T5. I have thought about what I would want when I get really sick				

T6. I have thoughts that my illness will not get better				
T7. I think about having an advanced directive				
T8. I think about the things I still want to do in this life				
T9. I think about my preferences for treating my illness in the future				
T1. I have thoughts about people I value				
T11. I think about my values that I want to maintain at the end of life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not clear and representative of the concept of *Thinking* ***within*** **the construct of preparedness for advance care planning.**

Comment/Suggestions
T1
T2
T3
T4
T5
T6
T7
T8
T9
T10
T11

Please suggest any additional items you feel would improve the measurement of **Thinking** or make any further comments to help improve this subscale

Domain 4: Willingness	***Item Clarity Rating***			
Definition: The readiness to participate in advance care planning	***(1) Not Clear***	***(2) Somewhat Clear***	***(3) Quite Clear***	***(4) Highly Clear***

W1. I am not willing to engage in advance care planning				
W2. I am willing to express my wishes in advance about limiting intensive care treatments				
W3. I am willing to go along with a request to discuss my end of life wishes				
W4. I am not willing to talk about health care issues related to end of life				
W5. I am willing to talk about my illness with family members that are important to me				
W6. I am willing to talk about my end of life with my doctors and nurses				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not clear and representative of the concept of Willingness within the construct of preparedness for advance care planning.

Comments/Suggestions
W1
W2
W3
W4
W5
W6

Please suggest any additional items you feel would improve the measurement of **Willingness** or make any further comments to help improve this subscale

Domain 5: Existential Reflection	***Item Clarity Rating***			
Definition: The individual's psyche thoughtful reflection on one's mortality, meaning of life,	***(1) Not***	***(2)***	***(3) Quite***	***(4) Highly***

assumptions about life, death, and quantity vs. quality of life while exploring EOL decisions.	***Clear***	***Somewhat Clear***	***Clear***	***Clear***
E1. I have an illness that is life threatening				
E2. I do not have a condition that will cause my death				
E3. I want to focus on the meaning of life when I approach to the end of life				
E4. I can imagine a scenario where my illness or other incidents will cause my death				
E5. I am peaceful when reflecting about the end of my life.				
E6. I am satisfied with the meaning I have given to my life				

Please comment on these items including possible revisions or substitutions, or your views as to why an item is not clear or representative of the concept of *Existential Reflection* within the construct of preparedness for advance care planning.

Comment/Suggestions
ER1
ER2
ER3
ER4
ER5
ER6

Please suggest any additional items you feel would improve the measurement of **Existential Reflection** or make any further comments to help improve this subscale

---

Debriefing Qualitative Questions for Comprehensiveness & Comprehensibility

Debriefing questions will use a semi-structured interview guide. The interview guide will contain questions about the participant's understanding of the instrument, the intended meaning and relevance of the items and response options, and general questions about the overall instrument and missing concepts

---

Comprehensiveness will be assessed by asking if all the key concepts have been included.

Comprehensibility will be assessed by asking

1. Are the questionnaire instruct**ions understood** by the population of interest as intended?
2. Are the items in the questionnaire appropriately worded?
3. If the response options match the question

APPENDIX C Demographic Sheet

Screening questions answered before reading the informed consent:

Do you have a chronic illness? Yes No
What is today's date?
Who is the current President of the United State?

Sociodemographic and clinical information:

Which of the following chronic illness do you have? (Select all that apply)
Heart Failure, Cancer, Diabetes, Kidney Failure, COPD, Stroke, Cardiovascular Illness, other _______
For the primary illness, how long have you been diagnosed with? _____
How many times have you been hospitalized because of the chronic illness in the past year?

What is your gender?
Male,
Female,
Transgender
Non-Binary
What is your age? ________ (fill in the blank, actual age)
What is your marital status?
Married, Widowed, Divorced, Never Married
What is your highest level of education completed?
Elementary (0-8 years),
Some high school (1-3 years),
High school graduate, Some college (1-3 years),
College graduate,
Some graduate school,
Completed graduate school
What is your religious affiliation?
Agnostic, Atheist, Buddhist, Catholic, Hindu, Jewish,
Muslim. Protestant, Jehovah Witness, Other (Please Specify)
Does your religious affiliation have a role in your end-of-life decisions?
Yes No
What is your race?
Asian, Black, Non-Hispanic White Pacific Islander, Hispanic/Latino White,
Multiracial, Other (please specify)
Do you have someone who cares for you and will support you at end of life?
Yes No

a. If yes, what is their relationship to you ______________________

Has anyone close to you died in the past two years? Yes No
Have you ever had a discussion about advance directives? Yes No
Have you had end of life conversations with your health provider before? Yes No
Have you heard about advance directives before? Yes No

Have you received information about advance directives before? Yes No
If yes; who told you about advance directives?
health care professional, family member, friend or other
Do you have a health care proxy? Yes No
Have you completed a living will? Yes No
Have you provided written directions about the medical treatment you want if you cannot make those decisions yourself? Yes No
Have you completed a Medical (Physician) Order of Life Sustain Treatment? (e.g., MOLST, POLST)? Yes No
Do you intend to complete an advanced directive?
In the next 6 months; ‘‘not at all likely’’ “likely” ‘‘highly likely”
In the next 30 days: ‘‘not at all likely’’ “likely” ‘‘highly likely”

Do you live alone? Yes No

Are you a health care provider? Yes No If yes what type of health provider?
What is your current health status?
‘Relatively healthy,’’
“Have an illness that will go away within 90 days”
“Have illness that is being treated chronically”
‘‘Seriously but not terminally ill,’’ or ‘‘
Seriously and terminally ill.’

APPENDIX D Advance Care Planning Readiness Instrument (ACPRI)

© Amy O. Calvin, Houston, Texas (2004)

We are interested in your thoughts about the care you are receiving now and in the future. Please circle the number below to show how much you disagree (lower number) or how much you agree (higher number) with each statement.

	Completely disagree →→ Completely Agree						
1. I worry about what my family and friends will do without me.	1	2	3	4	5	6	7
2. I find it helpful to talk about the end of my life.	1	2	3	4	5	6	7
3. I can relax and rely on most of the nurses and doctors to take good care of me.	1	2	3	4	5	6	7
4. Most nurses and doctors here don't seem to really care about me.	1	2	3	4	5	6	7
5. Most of my nurses and doctors pay attention to what I have to say.	1	2	3	4	5	6	7
6. Most nurses and doctors will do what's right for me.	1	2	3	4	5	6	7
7. I don't want my family and friends to worry about my bills.	1	2	3	4	5	6	7
8. I don't like to think about dying.	1	2	3	4	5	6	7
9. I want to focus on living life in a way that means something to me	1	2	3	4	5	6	7
10. I can't make decisions about the end of my life ahead of time because there are too many things, I'm not sure of right now.	1	2	3	4	5	6	7
11. I try to make sure nurses and doctors don't make mistakes when caring for me.	1	2	3	4	5	6	7
12. I have the freedom to make choices about what I want or don't want.	1	2	3	4	5	6	7
13. Most nurses and doctors here seem to think I want to keep enjoying life as long as I can.	1	2	3	4	5	6	7

14. As I approach the end of my life, I have family/friends that I can trust to make decisions for me.	1	2	3	4	5	6	7
15. I don't want to give up everything in my life.	1	2	3	4	5	6	7
16. Most nurses and doctors treat me like I don't exist anymore.	1	2	3	4	5	6	7
17. I'm not sure I can trust most of my nurses and doctors.	1	2	3	4	5	6	7
18. Writing down what I want to happen to me at the end of my life will allow me to die with dignity.	1	2	3	4	5	6	7
19. Sometimes I have to do what I have to do even though I know the end is coming	1	2	3	4	5	6	7
20. Making medical treatment plans (for example, planning or not planning for CPR) ahead of time help protect me and my wishes.	1	2	3	4	5	6	7
21. I want everything possible to keep me alive.	1	2	3	4	5	6	7
22. My family and friends need me.	1	2	3	4	5	6	7
23. At the end of my life, I talk to my family/friends about what I want to be done to me in the hospital.	1	2	3	4	5	6	7
24. Making medical treatment plans ahead of time (advance directives) does not guarantee that my wishes will be followed.	1	2	3	4	5	6	7
25. There is too much I don't know right now for me to make end-of-life decisions.	1	2	3	4	5	6	7
26. Most nurses and doctors seem to treat me like I'm dying.	1	2	3	4	5	6	7
27. I watch out for myself to make sure nothing goes wrong.	1	2	3	4	5	6	7
28. I know my family/friends will do what is best for me.	1	2	3	4	5	6	7

29. My family and friends may feel guilty if they have to decide to "pull the plug."	1	2	3	4	5	6	7
30. Most nurses and doctors listen to my opinions.	1	2	3	4	5	6	7

End Time: _____________

Please share with me your comments:

Thank you for your time and assistance.

APPENDIX E Mishel Uncertainty in Illness Scale (MUIS- C)

Instructions:

Please read each statement. Take your time and think about what each statement says. Then circle the answer that most closely measures how you are feeling TODAY. If you agree with a statement, then you would circle either “Strongly Agree” or “Agree”. If you disagree with a statement, then circle either “Strongly Disagree” or “Disagree. If you are undecided about how you feel, then circle “Cannot Decide” for that statement. Please respond to every statement. There are no right or wrong answers, and your response is correct.

Question	Strongly Agree	Agree	Cannot Decide	Disagree	Strongly Disagree
1. I don’t know what is wrong with me.					
2. I have a lot of questions.					
3. I am unsure if my illness is getting better or worse.					
4. It is unclear how bad my pain will be.					
5. The explanations they give about my condition seem hazy to me.					
6. The purpose of each treatment is clear to me.					
7. My symptoms continue to change unpredictably.					
8. I understand everything explained to me.					
9. The doctors say things to me that could have many meanings.					
1. My treatment is too complex to figure out.					
11. It is difficult to know if the treatments or medications I am getting are helping.					
12. Because of the unpredictability of my illness, I cannot plan for the future.					
13. The course of my illness keeps changing. I have good and bad days.					
14. I have been given many differing opinions about what is wrong with me.					
15. It is not clear what is going to happen to me.					
16. The results of my tests are inconsistent.					
17. The effectiveness of the treatment is undetermined.					
18. Because of the treatment, what I can do and cannot do keeps changing.					

19. I’m certain they will not find anything else wrong with me.				
2. The treatment I am receiving has a known probability of success.				
21. They have not given me a specific diagnosis.				
22. The seriousness of my illness has been determined.				
23. The doctors and nurses use everyday language so I can understand what they are saying.				

APPENDIX F Peace, Equanimity, and Acceptance in the (Chronic Illness) * Experience (PEACE) Scale

Circle the number for the answer that best describes how you are feeling now:

1 = Not at all
2 = To a slight extent
3 = To some extent
4 = To a large extent

Peaceful Acceptance of Illness Subscale

1. To what extent are you able to accept your diagnosis of illness? 1 2 3 4
2. To what extent would you say you have a sense of inner peace and harmony? 1 2 3 4
3. To what extent do you feel that you have made peace with your illness? 1 2 3 4
4. Do you feel well loved now? 1 2 3 4
5. To what extent do you feel a sense of inner calm and tranquility? 1 2 3 4

Struggle With Illness Subscale

1. To what extent do changes in your physical appearance upset you? 1 2 3 4
2. To what extent does worry about your illness make it difficult for you to live from day to day? 1 2 3 4
3.* To what extent do you feel that it is unfair for you to have a chronic illness now? 1 2 3 4
4. To what extent do you feel that your life, as you know it, is now over? 1 2 3 4
5. To what extent do you feel angry because of your illness? 1 2 3 4
6. To what extent do you think your illness has beaten you down? 1 2 3 4
7. To what extent do you feel ashamed of, or embarrassed by, your current condition? 1 2 3 4

APPENDIX G Short Health Anxiety Inventory (HAI-18) (psychology-tools.com)

Each of the following questions consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes how you have felt over the past six months. If you find that more than one statement applies, please select any of the applicable statements.

1. *a.)* I do not worry about my health.
b.) I occasionally worry about my health.
c.) I spend much of my time worrying about my health.
d.) I spend most of my time worrying about my health.

2. *a.)* I notice aches/pains less than most other people (of my age).
b.) I notice aches/pains as much as most other people (of my age).
c.) I notice aches/pains more than most other people (of my age).
d.) I am aware of aches/pains in my body all the time.

3. *a.)* as a rule, I am not aware of bodily sensations or changes.
b.) sometimes I am aware of bodily sensations or changes.
c.) I am often aware of bodily sensations or changes.
d.) I am constantly aware of bodily sensations or changes.

4. *a.)* resisting thoughts of illness is never a problem.
b.) most of the time I can resist thoughts of illness.
c.) I try to resist thoughts of illness but am often unable to do so.
d.) thoughts of illness are so strong that I no longer even try to resist them.

5. *a.)* as a rule, I am not afraid that I have a serious illness.
b.) I am sometimes afraid that I have a serious illness.
c.) I am often afraid that I have a serious illness.
d.) I am always afraid that I have a serious illness.

6. *a.)* I do not have images (mental pictures) of myself being ill.
b.) I occasionally have images of myself being ill.
c.) I frequently have images of myself being ill.
d.) I constantly have images of myself being ill.

7. *a.)* I do not have any difficulty taking my mind off thoughts about my health.
b.) I sometimes have difficulty taking my mind off thoughts about my health.
c.) I often have difficulty in taking my mind off thoughts about my health.
d.) Nothing can take my mind off thoughts about my health.

8. *a.)* I am lastingly relieved if my doctor tells me there is nothing wrong.
b.) I am initially relieved, but the worries sometimes return later.
c.) I am initially relieved, but the worries always return later.
d.) I am not relieved if my doctor tells me there is nothing wrong.

9. *a.)* if I hear about an illness, I never think I, have it myself.
b.) if I hear about an illness, I sometimes think I, have it myself.
c.) if I hear about an illness, I often think I, have it myself.
d.) if I hear about an illness, I always think I, have it myself.

1. *a.)* if I have a bodily sensation or change, I rarely wonder what it means.
b.) if I have a bodily sensation or change, I often wonder what it means.
c.) if I have a bodily sensation or change, I always wonder what it means.

d.) if I have a bodily sensation or change, I must know what it means.

11. a.) I usually feel at very low risk for developing a serious illness.
b.) I usually feel at fairly low risk for developing a serious illness.
c.) I usually feel at moderate risk for developing a serious illness.
d.) I usually feel at high risk for developing a serious illness.

12. *a.)* I never think I have a serious illness.
b.) I sometimes think I have a serious illness.
c.) I often think I have a serious illness.
d.) I usually think that I am seriously ill.

13. *a.)* if I notice an unexplained bodily sensation, I don't find it difficult to think about other things.
b.) if I notice an unexplained bodily sensation, I sometimes find it difficult to think about other things.
c.) if I notice an unexplained bodily sensation, I often find it difficult to think about other things.
d.) if I notice an unexplained bodily sensation, I always find it difficult to think about other things.

14. *a.)* my family/friends would say I do not worry enough about my health.
b.) my family/friends would say I have a normal attitude to my health.
c.) my family/friends would say I worry too much about my health.
d.) my family/friends would say I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness of a type which particularly concerns you (e.g., heart disease, cancer, multiple sclerosis & so on). Obviously, you cannot know for definite what it would be like; please give your best estimate of what you *think* might happen, basing your estimate on what you know about yourself and serious illness in general.

15. *a.)* if I had a serious illness, I would still be able to enjoy things in my life quite a lot.
b.) if I had a serious illness, I would still be able to enjoy things in my life a little.
c.) if I had a serious illness, I would be almost completely unable to enjoy things in my life.
d.) if I had a serious illness, I would be completely unable to enjoy life at all.

16. *a.)* if I developed a serious illness there is a good chance that modern medicine would be able to cure me.
b.) if I developed a serious illness there is a moderate chance that modern medicine would be able to cure me.
c.) if I developed a serious illness there is a very small chance that modern medicine would be able to cure me.
d.) if I developed a serious illness there is no chance that modern medicine would be able to cure me.

17. *a.)* a serious illness would ruin some aspects of my life.
b.) a serious illness would ruin many aspects of my life.
c.) a serious illness would ruin almost every aspect of my life.
d.) a serious illness would ruin every aspect of my life.

18. *a.)* if I had a serious illness, I would not feel that I had lost my dignity.
b.) if I had a serious illness, I would feel that I had lost a little of my dignity.
c.) if I had a serious illness, I would feel that I had lost quite a lot of my dignity.
d.) if I had a serious illness, I would feel that I had totally lost my dignity.

---

all groups are scored 0, 1, 2 or 3 depending on the statement selected.
if more than statement is selected, use the highest-scoring statement of those chosen.

main section score (questions 1 to 14) =

negative consequences score (questions 15 to 18) =

total score =

scoring the 18 item HAI

In the 2002 paper describing the development of both the full Health Anxiety Inventory and this current shortened 18 item version, the following scores were reported for the shortened form in a series of different populations. The table below gives means (and standard deviations):

	health anxiety	*anxiety sufferers*	*controls*	*students*	*gp patients*	*gastro patients*
main section	3.1 (5.5)	14.9 (6.2)	9.4 (5.1)	9.6 (4.5)	11.2 (4.6)	11.4 (6.3)
negative consequences	7.8 (2.8)	3.6 (2.2)	2.2 (2.1)	3.0 (1.8)	3.2 (2.0)	2.4 (1.9)
total score	37.9 (6.8)	18.5 (7.3)	12.2 (6.2)	12.6 (5.0)	14.5 (5.9	13.9 (7.4)

Salkovskis P.M., Rimes K.A., Warwick H.M.C. & Clark D.M. *The health anxiety inventory: development and validation of scales for the measurement of health anxiety and hypochondriasis* Psychological Medicine 2002; 32:843-853

APPENDIX H **Socially Desirable Response Set 5-item Survey** (SDRS-5, Hays, Hayashi & Stewart, 1989)

1. I am always courteous even to people who are disagreeable.
2. There have been occasions when I took advantage of someone.
3. I sometimes try to get even rather than to forgive and forget.
4. I sometimes feel resentful when I don't get my way.
5. No matter who I'm talking to, I'm always a good listener.

1 = Definitely True,
2 = Mostly True,
3 = Don't Know,
4 = Mostly False,
5 = Definitely False
Items one and five are reverse scored
This instrument can be found at: http://www.rand.org/health/surveys_tools/sdrs.html

APPENDIX I:

Informed Consent

Welcome to the Advance Planning Preparedness Research Study

Research purposes: Renee McLeod-Sordjan, a PhD student at Adelphi University is conducting research on individuals with chronic illness and their emotional and cognitive state related to advance care planning. The purpose of your participation in this research is to help the researcher determine the relevance of potential survey items to the construct of advance planning preparedness.

Description of research: You will complete a survey that asks about your readiness to perform advance care planning. Additionally, you will complete survey questions related to readiness for advance care planning, health anxiety, uncertainty of chronic illness and health related anxiety. The expected time considerations to complete this is 45 to 60 minutes. At the end of the survey, you may choose to complete the survey related to readiness for advance care planning in 48 to 96 hours. You will be asked to supply an email. The expected time of the repeat survey is 20 to 30 minutes.

Potential risks: The questions in the survey will ask you to reflect on the potential of chronic illness at end of life and the sensitive topic of planning for death. The potential risk is that this may bring up uncomfortable emotions and memories. Should you need to discuss these emotions you will be referred to discuss these emotions through SAMHSA’s Treatment Referral and Routing Service, 1-800-662-HELP.

Potential benefits: There will be no direct benefit to you from participating in this research study. You were selected as a possible participant in this study because you have content expertise in living with a chronic illness. The anticipated benefit of your participation in this study is advancing knowledge and practice to assist individuals with chronic illness obtain advance care planning assistance earlier in their care.

Costs/Compensation: There is no cost to you for completing this study and you will not receive any monetary compensation. Contact persons: If you have any questions at any time about this research or want to discuss any possible study-related incidents, please contact Renee McLeod-Sordjan PhD student at 347-612-5617 and/or renee.mcleodsordjan@adelphi.edu. You may also contact Dr. Y. Sun, at ysun@adelphi.edu

Confidentiality: All efforts will be maintained to protect your privacy and confidentiality. Your identity as a participant in this research study will be kept confidential in any publication of the results of this study. The records from this study will be kept as confidential as possible. No individual identities will be used in any reports or publications resulting from the study. All surveys and questionnaire data will be given codes and stored separately from any names or other direct identification of participants. Research information will be kept in locked files at all times. Only research personnel will have access to the files and only those with an essential need to other identifying information will have access to that particular file. After the study is completed collected data will be retained for seven years and then destroyed. The information obtained during this research will be kept confidential to the extent permitted by law. However, this research record may be reviewed by government agencies (such as the Department of Health and Human services), individuals who are authorized to monitor or audit the research or the Institutional Review Board (the committee that oversees all research in human subjects at Adelphi University), if required by applicable laws or regulations. All data and material related to this research will be maintained for up to seven years.

Voluntary participation: Participation in this study is voluntary. Your decision whether or not to participate in this study is voluntary and will not affect your relationship with Adelphi University or the researcher, if you choose to participate in this study, you can withdraw your consent and discontinue participation at any time without prejudice. Any new information that develops during this study, which might affect your decision to participate, will be given to you immediately. A signed copy of this consent form will also be given to you.

Institutional Review Board approval: This research has been reviewed and approved by the Adelphi University Institutional Review Board. If you have any questions, concerns, or comments, please contact the IRB chair, Dr. Carolyn Springer, 516-877-4753; springer@adelphi.edu

UPON CLICKING THE NEXT SCREEN, YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN A RESEARCH STUDY. YOUR ELECTRONIC SIGNATURE BELOW INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE IN THE STUDY AFTER READING ALL OF THE INFORMATION ABOVE AND YOU UNDERSTAND THE INFORMATION IN THIS FORM AND CAN DOWNLOAD A COPY OF THIS FORM FOR YOU TO KEEP.

By clicking the button below, you acknowledge:

- Your participation in the study is voluntary.
- You are 18 years of age.
- You are aware that you may choose to terminate your participation at any time for any reason.

I consent, begin the study
I do not consent, I do not wish to participate

APPENDIX J:

Pilot Test Feedback Sample Questions

Introduction: You will be asked to share your experience of taking the APPS. You will be asked to evaluate the APPS instructions, items, and response options.

1. Display
    a. Were the number of the questions shown on each page acceptable
    b. Were the arrangement of the items on the display easy to use
    c. Were there any items that had the potential to be missed (not answered)
    d. What are some of the causes that items were missed?
2. Relevance
    a. Are the items in APPS relevant for individuals with chronic illness?

3. Clarity
    a. Were the instructions of the scale clear?
    b. Was the wording of the items clear?

4. Comprehensibility
    a. Were the questionnaire instructions understandable?
    b. Are the items in the questionnaire appropriately worded?
    c. Do the response options match the question?

5. Please suggest any additional items you feel would improve the measurement of *Preparedness for advance care planning* or make any further comments to help improve this scale.

6. Were there any questions you were uncomfortable asking

7. Were there any other concerns about the survey

Closing Thank you for taking the time to participate today. Your feedback will be collected and is reported anonymously.

APPENDIX K:

ARE YOU PREPARED?

If you are 18 or older and have one or more illnesses that you take medications for, you may be eligible to participate in a research study.

Study for Adults Exploring Attitudes About Advanced Directives

We are looking for adults 18 years and older to survey about your attitudes and emotions related to discussing your wishes and values for medical treatment at the end of life.

Many people have trouble talking to their family and health care provider about what medical care they would like in case they were unable to get better.

This research will help nurses and other providers understand when people with illnesses are ready to talk about end-of-life medical care.

Participants will not receive:
- ☐ Compensation

Location
- ☐ Online Qualtrics Survey
- ☐ **WILL PUT THE QR CODE HERE**

Are you eligible?
- ☐ You are 18 years or older
- ☐ You have an illness
- ☐ You are able to read and write in English

If you're unsure if you meet the requirements, call or email a member of the study team:

Renee McLeod-Sordjan, RN, DNP,
PhD Nursing Student
Principal Investigator
Renee.mcleodsordjan@adelphi.edu
347-612-5617

Faculty Advisor Dr. Y Sun
College of Nursing & Public Health
YSUN@adelphi.edu
516-877-4564

INSERT WEBSITE URL HERE (THIS WILL BE QUALTRICS URL)

ADELPHI UNIVERSITY | ONE SOUTH AVENUE, GARDEN CITY, NY 11530 | 516.877.4564

ADELPHI UNIVERSITY PhD NURSING STUDENT

ADELPHI UNIVERSITY PhD NURSING STUDENT PROJECT

APPENDIX L:

Debriefing

Thank you for your participation. The study in which you have served as a participant is concerned with emotional and psychological preparedness for advance care planning. You have aided the researcher in creating a survey to explore whether a person is reading to have conversations about their wishes at end of life. The hypothesis for this study is that this newly developed tool will better predict readiness for advance care planning. You filled out some demographic questions and five questionnaires. The practical application of this research concerns how to help doctors, nurses and researchers assist individuals with chronic illness make decisions in advance that are consistent with their wishes and values. There is no compensation for completing this survey. If you have any questions about this research, or if you would like a copy of the results, please email Dr. Renee McLeod-Sordjan at renee.mcleodsordjan@adelphi.edu

APPENDIX M:

Pearson’s Correlation Table Demographics APPS and Subscales

		APPS35	PSYCHE COMFORT	DESIRE TO KNOW	THINKING	WILLING	EXISTENT AL
APPS35	Pearson’s	1	.913**	.914**	.849**	.849**	.860**
	N	543	543	543	543	543	543
Experience with AD	Pearson’s	.226**	.254**	.149**	.248**	.204**	.144
	N	543	543	543	543	543	543
Employed	Pearson’s	.104*	.129**	.064	.083	.066	.105
	N	534	534	534	534	534	534
Hispanic	Pearson’s	-.092*	-.078	-.120**	-.119**	-.003	-.070
	N	535	535	535	535	535	535
Health Provider	Pearson’s	.104*	.135**	.106**	.112**	-.005	.068
	N	537	537	537	537	537	537
Social Support at EOL	Pearson’s	.111**	.100*	.119**	.122**	.107*	.047
	N	541	541	541	541	541	541
Death of Loved 1 In 2 Yrs	Pearson’s	.059	.021	.040	.051	.120**	.057
	N	540	540	540	540	540	540
Know an AD	Pearson’s	.098*	.074	.102*	.093*	.096*	.073
	N	541	541	541	541	541	541
Have an AD	Pearson’s	.183**	.192**	.144**	.184**	.129**	.149
	N	452	452	452	452	452	452
Heard about ADs	Pearson’s	.029	.022	.023	.043	-.045	.077
	N	216	216	216	216	216	216
Past info about ADs	Pearson’s	.159**	.153**	.146**	.164**	.121**	.112**
	N	540	540	540	540	540	540
Comm. with HCP	Pearson’s	.129**	.122**	.091*	.149**	.099*	.127**
	N	530	530	530	530	530	530
Intent to complete AD 30 day	Pearson’s	.236**	.255**	.168*	.233**	.184*	.232*
	N	157	157	157	157	157	157

Intent to complete AD 180	Pearson's	.189**	.203**	.174*	.109	.151*	.175*
	N	196	196	196	196	196	196
Know a health proxy	Pearson's	.184**	.201**	.142**	.170**	.140**	.150**
	N	536	536	536	536	536	536
Have a health proxy	Pearson's	.180**	.212**	.144**	.167**	.156**	.105*
	N	497	497	497	497	497	497
Know a living will	Pearson's	.135**	.086*	.155**	.133**	.118**	.099*
	N	533	533	533	533	533	533
Have a living will?	Pearson's	.119**	.138**	.107*	.120**	.058	.080
	N	513	513	513	513	513	513
EOL Convo HCP	Pearson's	.186**	.182**	.171**	.191**	.134**	.150**
	N	535	535	535	535	535	535
Written EOL Plan	Pearson's	.122**	.138**	.103*	.131**	.088*	.068
	N	534	534	534	534	534	534
Verbal EOL Plan	Pearson's	.135**	.141**	.137**	.134**	.102*	.073
	N	537	537	537	537	537	537
Know MOLST, POLST	Pearson's	.161**	.164**	.117**	.150**	.129**	.158**
	N	535	535	535	535	535	535
Have MOLST,	Pearson's	.130**	.149**	.094*	.138**	.068	.111**
	N	499	499	499	499	499	499
Mortality Understand	Pearson's	-.108*	-.103*	-.102*	-.130**	-.038	-.111**
	N	542	542	542	542	542	542
Total Chronic Illness	Pearson's	.118*	.102*	.091*	.155**	.089*	.091*
	N	543	543	543	543	543	543

**Correlation is significant at the .01 level (2-tailed)

*Correlation is significant at the .05 level (2-tailed)

APPENDIX N:

Pearson Correlations of APPS

		APPS35
Experiences with either ACP or AD for yourself or a loved one	Pearson Correlation	.226**
	N	543
Gender	Pearson Correlation	.085*
	Sig. (2-tailed)	.047
	N	542
Age	Pearson Correlation	-.047
	N	542
Marital status?	Pearson Correlation	.086*
	N	542
Do you live alone?	Pearson Correlation	-.077
	N	529
Education	Pearson Correlation	.163**
	N	542
Employment Status	Pearson Correlation	.104*
	N	534
Hispanic, Latino, or Spanish origin?	Pearson Correlation	-.092*
	N	535
Are you a health care provider?	Pearson Correlation	.104*
	N	537
Religious affiliation has an effect on your end-of-life decisions	Pearson Correlation	.088*
	N	530
Social support toward the end of life	Pearson Correlation	.111*
	N	541
Has anyone close to you died in the past two years?	Pearson Correlation	.059
	N	540
Know what an advance directive	Pearson Correlation	.098*
	N	541
Have an advance directive	Pearson Correlation	.183**
	N	452
Heard about advance directives	Pearson Correlation	.029
	N	216
Received information about advance directives	Pearson Correlation	.159**
	N	540
Routine discussion about AD with a health care provider	Pearson Correlation	.129**
	N	530
Intent to complete an advance directive in the next 30 days	Pearson Correlation	.236**
	N	157
Intent to complete an advance directive in the next 6 months	Pearson Correlation	.189**
	N	196
Know what a health care proxy is?	Pearson Correlation	.184**
	N	536
Have a health care proxy?	Pearson Correlation	.180**
	N	497

Know what a living will is	Pearson Correlation	.135**
	N	533
Completed a living will	Pearson Correlation	.119**
	N	513
EOL conversation with health provider	Pearson Correlation	.186**
	N	535
Provided written directions about the medical treatment you want if you cannot make those decisions yourself?	Pearson Correlation	.122**
	N	534
Provided verbal directions about the medical treatment you want if you cannot make those decisions yourself?	Pearson Correlation	.135**
	N	537
Know what a Medical (Physician) Order of Life Sustaining Treatment (e.g., MOLST, POLST) is?	Pearson Correlation	.161**
	N	535
Completed a Medical (Physician) Order of Life Sustaining Treatment (e.g., MOLST, POLST)?	Pearson Correlation	.130**
	N	499
Current health status	Pearson Correlation	-.043
	N	542
Understanding of how long you may live?	Pearson Correlation	-.108*
	N	542

*p<.05 **p<.01

APPENDIX O

ANOVA: Between and Within Group Analysis of Having, Not Having and Unsure of Having advance directives

		Sum of Squares	df	Mean Square	F	Sig.
APPS35	Between Groups	4.544	2	2.272	7.830	<.001
	Within Groups	130.290	449	.290		
	Total	134.835	451			
ACCEPTANCE	Between Groups	3.243	2	1.621	6.583	.002
	Within Groups	110.579	449	.246		
	Total	113.822	451			
STRUGGLE WITH ILLNESS	Between Groups	4.682	2	2.341	8.980	<.001
	Within Groups	117.054	449	.261		
	Total	121.736	451			
HEALTH ANXIETY	Between Groups	4.857	2	2.429	2.316	.100
	Within Groups	470.867	449	1.049		
	Total	475.725	451			
ACPRI	Between Groups	5.546	2	2.773	11.639	<.001
	Within Groups	106.975	449	.238		
	Total	112.521	451			
UNCERTAINTY	Between Groups	2.258	2	1.129	4.069	.018
	Within Groups	124.581	449	.277		
	Total	126.839	451			

APPENDIX P

Spearman's Rho Correlations Coefficients

			APPS35	Have you had experiences with either advance care planning or advance directives for yourself or a loved one	Are you employed?	What is your current health status?	What is your understanding of how long you may live?	What is your gender? - Selected Choice	What is the highest degree or level of school you have completed?	Are you of Hispanic, Latino, or Spanish origin?
Spearman's rho	MEANPAPPS35	Correlation Coefficient	1 000	178**	108*	- 059	- 122**	053	100*	- 126**
		N	543	543	534	542	542	542	542	535
	Experiences with either advance care planning or advance directives for yourself or a loved one	Correlation Coefficient	178**	1 000	161**	083	- 160**	063	048	040
		N	543	543	534	542	542	542	542	535
	Are you employed?	Correlation Coefficient	108*	161**	1 000	- 074	- 176**	- 021	219**	- 040
		N	534	534	534	534	533	533	534	528
	What is your current health status?	Correlation Coefficient	- 059	083	- 074	1 000	- 068	- 004	- 082	038
		N	542	542	534	542	541	541	542	535
	What is your understanding of how long you may live?	Correlation Coefficient	- 122**	- 160**	- 176**	- 068	1 000	019	022	150**
		N	542	542	533	541	542	541	541	534
	What is your gender? - Selected Choice	Correlation Coefficient	053	063	- 021	- 004	019	1 000	058	030
		N	542	542	533	541	541	542	541	534
	What is the highest degree or level of school you have completed?	Correlation Coefficient	100*	048	219**	- 082	022	058	1 000	004
		N	542	542	534	542	541	541	542	535
	Are you of Hispanic, Latino, or Spanish origin?	Correlation Coefficient	- 126**	040	- 040	038	150**	030	004	1 000
		N	535	535	528	535	534	534	535	535

** Correlation is significant at the 0 01 level (2-tailed)

* Correlation is significant at the 0 05 level (2-tailed)

APPENDIX Q: IRB Approval

ADELPHI
UNIVERSITY

INSTITUTIONAL REVIEWBOARD
T 516-877-3259
F 516-877-3297
adelphi.edu
PO Box 701
ONE SOUTH AVENUE
GARDEN CITY NEW YORK 11530

ADELPHI.EDU

June 30, 2022

Ms. Renee McLeod-Sordjan
College of Nursing and Public Health
Adelphi University
Garden City, NY
11530

Dear Ms. McLeod-Sordjan:

The Institutional Review Board (IRB) has met and reviewed your proposal, *Development and Validation of the Advance Planning Preparedness Scale (APPS) (Submission* #061322), and the committee has granted your proposal exemption. Should you wish to make any modifications to your research, you are required to submit an amendment to the IRB to have your classification as exempt reconfirmed. Please note that you remain obligated to observe the Belmont principles with respect to the protection of human subjects.

If you have any questions, please feel free to contact me at 516-877-4753 or e-mail me at springer@adelphi.edu

Sincerely,

Carolyn Springer, Ph.D., Chair
Adelphi University Institutional Review Board

CC: Dr. Y. Sun

Appendix R:

Inspired Life Church
5660 Harrisburg Industrial Park Drive, Harrisburg, North Carolina 28075
(704) 455-1540 or **(704) 455-7774**
Email: **inspiredlifech@yahoo.com** • Website: **inspiredlifech.org**
Johnny E. Brown II, Lead Pastor • Stacey L. Brown, Executive Pastor

To whom it may concern,

Too often people in a community do not have living wills or advanced directives. This causes a lot of distress at the end of life as families are unsure what their loved ones' wishes are and how to carry them out.

The work of Dr. McLeod-Sordjan is so important to our church community and the community as a whole. As the administrator of Inspired Life Church in North Carolina, I support her research entitled the *Development and Validation of the Advanced Planning Preparedness Scale (APPS)*.

Our church would be honored to allow Renee McLeod-Sordjan, as a PhD student of Adelphi University, to disseminate her informative flyers to potential participants with chronic illnesses to research their emotional and cognitive state related to advanced care planning.

Sincerely,

Tanya Y Blanding

Administrator, Inspired Life Church

"Where God's Word Ignites The Soul "

APPENDIX S:

From: Calvin, Amy O [mailto:Amy.O.Calvin@uth.tmc.edu]
Sent: Monday, June 16, 2014, 10:29 AM
To: Mcleod-Sordjan, Renee
Subject: RE: Regarding your Advance Care Planning Readiness Instrument

Ms. McLeod-Sordjan:
I am pleased that you are interested in my work that was developed with the hemodialysis patient population. I attached the instrument for your use. If you decide to use the Advance Care Planning Readiness Instrument (ACPRI), I would appreciate the following:

1. Acknowledge my publication(s) and me as the developer and source of the ACPRI.
2. Send me a copy of the data that is collected (de-identified, but with age, gender, and ethnicity) to add to the ACPRI database for factor analysis testing.

Theoretically, a low score on the ACPRI indicates advance care planning readiness or readiness to forgo end-of-life treatment and a high score indicates non-readiness to formulate advance directives and a desire for all life-sustaining treatment. The total possible personal preservation score is 210. Items 3, 5, 13, 18, 20, and 30 require reverse coding.

I have not done additional work on the ACPRI, as I was unable to secure funding for a larger study after the pilot.

Best regards,
Amy O. Calvin, PhD, RN

Associate Professor of Clinical Nursing
Director, Simulation & Clinical Performance Laboratory
The University of Texas Health Science Center
School of Nursing at Houston
6901 Bertner Avenue, Room 663
Houston, Texas 77030
713.500.2154 (office)
713.500.2171 (fax)

From: Mcleod-Sordjan, Renee
Sent: Saturday, June 14, 2014, 9:24 AM
To: Calvin, Amy O
Subject: Regarding your advance care planning Readiness Instrument

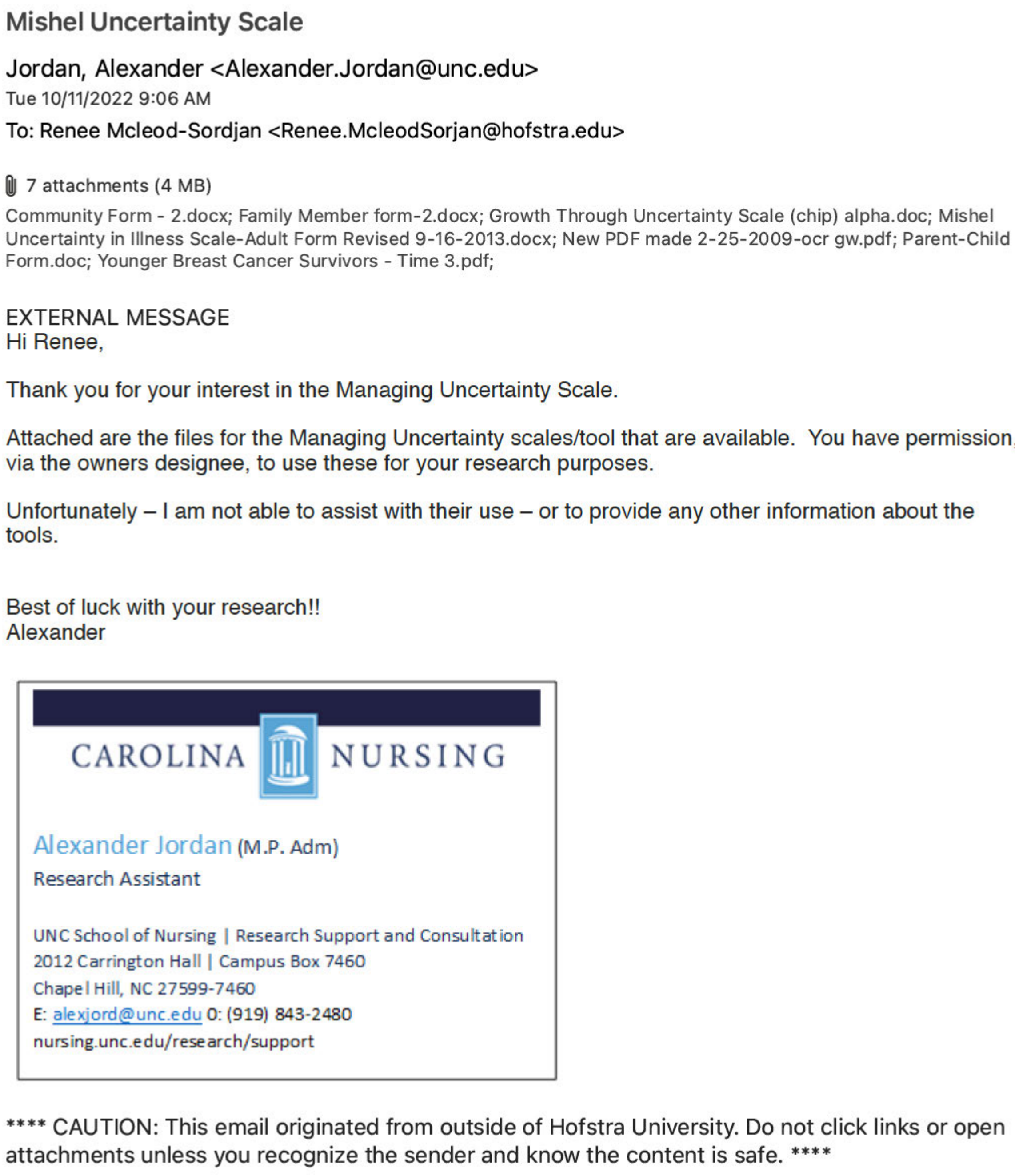
Dr. O' Calvin

It has been wonderful reading your work on your theory of personal preservation. Currently, I am a medical ethics consultant and became interested in assessing readiness for advance care planning with the outcome of a completion of the document. I am presently in the beginning of my third year as a PhD student at Adelphi University in NY and have developed a concept analysis on death preparedness. I am now planning my proposal of study.

I would like your permission to use the advance care planning readiness tool in individuals with chronic life limiting disease to assess their readiness to discuss advance care plans. I am also interested in additional reliability of your instrument in larger samples

Renee McLeod-Sordjan, DNP

APPENDIX T:



Mishel Uncertainty Scale

Jordan, Alexander <Alexander.Jordan@unc.edu>
Tue 10/11/2022 9:06 AM
To: Renee Mcleod-Sordjan <Renee.McleodSorjan@hofstra.edu>

7 attachments (4 MB)
Community Form - 2.docx; Family Member form-2.docx; Growth Through Uncertainty Scale (chip) alpha.doc; Mishel Uncertainty in Illness Scale-Adult Form Revised 9-16-2013.docx; New PDF made 2-25-2009-ocr gw.pdf; Parent-Child Form.doc; Younger Breast Cancer Survivors - Time 3.pdf;

EXTERNAL MESSAGE
Hi Renee,

Thank you for your interest in the Managing Uncertainty Scale.

Attached are the files for the Managing Uncertainty scales/tool that are available. You have permission, via the owners designee, to use these for your research purposes.

Unfortunately – I am not able to assist with their use – or to provide any other information about the tools.

Best of luck with your research!!
Alexander

CAROLINA NURSING

Alexander Jordan (M.P. Adm)
Research Assistant

UNC School of Nursing | Research Support and Consultation
2012 Carrington Hall | Campus Box 7460
Chapel Hill, NC 27599-7460
E: alexjord@unc.edu O: (919) 843-2480
nursing.unc.edu/research/support

**** CAUTION: This email originated from outside of Hofstra University. Do not click links or open attachments unless you recognize the sender and know the content is safe. ****

APPENDIX U:

Advanced Planning Preparedness Scale (Final-APPS-35)

Psychological comfort with advance care planning

3 I find it easy to talk about end-of-life related health care.
4 I feel at ease to discuss the pros and cons of life sustaining treatment at end of life.
5 I feel ready to discuss who should make health care decisions for me if I am unable to.
7 I am ready to make decisions about end-of-life health care ahead of time
9 I feel at ease when saying my feelings about getting sicker
11 I am comfortable with discussing my wishes at the end of life
13 I feel comfortable with discussing my health care choices at the end of life
15 I want to know the choices about treatments at the end of my life
38 I am satisfied with the meaning I have given to my life

Desire to know

8 I prefer to make an advance directive when I am healthy
12 I am open to discuss my emotions about a decline in my health
16 I want to know the nature of the medical problems I have
20 I need knowledge about illnesses that are life threatening
22 I prefer to have the true facts about whether my illness is terminal
24 I want to know the odds that I may lose ability to make my own health care choices.
28 I think about my preferences for end-of-life care
30 I think about my values I want to maintain at the end of life
32 If asked to, I will discuss my end of life wishes with my health care team
36 I want to focus on the meaning of life when I approach the end of life

Thinking

10 I feel ease with being asked about the things that are important to me
14 I desire to know more about advance care planning
18 I prefer to discuss the pros and cons of CPR at end of life
26 I have thought about what I would want when I get really sick
34 I am willing to talk about my end of life with my doctors and nurses

Willingness

17 I desire facts about my health to help me make my own end of life decisions
25 I have thought about my illnesses getting worse.
29 I have thoughts about people I value
31 I am willing to say my wishes ahead of time about limits to care at end of life
33 I am willing to talk about my illness with family that are dear to me

Existential Reflection

19 I want to know about a condition that will cause my imminent death
21 I want to have knowledge about a condition that will cause my death
23 I want to know what an advanced directive is
27 I think about the things I still want to do in this life.
35 I have an illness that is life threatening
37 I have imagined a scenario where my illness will cause my death