

“THERE’S NOTHING WRONG WITH YOU THAT AN EXPENSIVE OPERATION CAN’T
PROLONG”: AN EXPLORATION OF HEALTH LITERACY, END-OF-LIFE CARE
PREFERENCES, AND DEATH EXPOSURE

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A DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Psychology
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2020

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ABSTRACT

Health literacy influences the ways in which individuals access and utilize health information to promote well-being, and the following interrelated studies examined functional health literacy in community-dwelling adults in the context of advance care planning. When assessing health literacy, it is important to first establish basic functional levels of this construct, as this may provide crucial information regarding the ways in which patients interact with the healthcare system. Study One established the importance of assessing functional health literacy among older adults in a primary care context, as significant discrepancies were noted between patients' subjective reports of health literacy and their objective ability to understand and manipulate health information. This is an important trend to monitor, as it is becoming increasingly necessary for U.S. adults to make decisions regarding end-of-life care in collaboration with their medical providers. Functional health literacy is an important factor to consider in this context, as it may influence the care that patients desire at the end of life. Based on the findings in Study One regarding the importance of functional health literacy, Study Two examined ways in which functional health literacy and death exposure influenced preferred end-of-life interventions. It was found that these variables did not influence aggressiveness of end-of-life care choices; however, general knowledge of palliative care was low, and further research is needed to clarify how understanding of palliative care influences advance care planning. Finally, Study Three continued the exploration of end-of-life decision-making by examining attitudes towards physician-assisted death (PAD), an end-of-life intervention that is becoming

increasingly common within the United States. Factors such as religiosity and attitudes regarding PAD were found to influence individual support for the legalization of PAD. Furthermore, there was a significant positive association between health literacy and PAD, indicating that those with higher health literacy were more supportive of PAD, even within a sample of adults with low palliative care knowledge. Implications regarding these findings include the necessity of screening for functional health literacy, as well as assisting patients to engage in both informal and formal advance care planning as early as possible.

LIST OF ABBREVIATIONS AND SYMBOLS

α	Cronbach's alpha, a measure of internal consistency
β	Standardized regression coefficient
χ^2	Chi-square
COVID	Novel coronavirus 2019
df	Degrees of freedom
F	Fisher's F ratio: A ratio of two variances
M	Mean: the sum of a set of measurements divided by the number of measurements in the set
n	Sample size
p	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
r	Pearson product-moment correlation
SD	Standard deviation: amount of variation or dispersion of a set of data values
t	Computed value of t test
<	Less than
>	Greater than
=	Equal to
PAD	Physician-assisted death

ACKNOWLEDGEMENTS

I have been so very lucky to have the best mentors in Alabama. None of this would have been possible without Dr. Rebecca Allen, who never once gave up on me, even when pets were useless. I am honored to be the empress of her lab. Like all good imperial powers, I declared my new title and announced the beginning of my reign, and she was kind enough to humor me. While this is a lifelong position, it is ceremonial, as the Allen Lab cannot function without Becky as its leader. Let's not speak about the time I was in charge of lab meeting in her absence. In addition, I was lucky enough to find my clinical niche in gero-neuropsychology while working with Jedi Master Dr. John Burkhardt. Despite his best efforts, he did not succeed in turning me into a child psychologist. I also owe so much gratitude to Dr. Martha Crowther and the members of the Tuscaloosa Fire and Rescue Service. I'm not sure that anything I do will ever be cooler than ACTION, and I will never again look at a head of lettuce the same way. Finally, I would like to thank my committee members, Drs. Sheila Black, Anne Halli, Jim Hamilton, and Forrest Scogin, for their patience, wisdom, and support, as well as for their tolerance of minions on (many) official presentations over the years.

In addition to awesome mentors, I am so grateful to have made lifelong friends and mortal enemies while in Alabama. I miss their presence and companionship on a daily basis, and I look forward to many more years of laughter. While on internship, I was truly lucky to find equally wonderful friends and mentors, particularly in Dr. Allison Jahn, and these friendships made living in a big city far more tolerable and fun. And they taught me how to (sort of) drive in

snow and provided me with mittens and a car jump starter when they became concerned about my attitude towards winter. These things came in handy.

I would also like to thank and acknowledge my family for their continuous and unreserved support. My mom, who outranks me with an MD PhD, offered to pay me \$1 for every page of this dissertation that I completed. She owes me \$138 (references and acknowledgments count). My dad has helped with countless moves and participated in endless games of Pinochle, and he has an exceptional grasp of alphabetical order. I have the best of monkeys, who probably inserted a few typos into this document by stepping on the keyboard.

Lastly, while I ended up in geropsychology by accident, it was a perfect fit. I am lucky to have known and loved all four of my grandparents, and I hope I have gained wisdom from each of them. My maternal grandmother passed away in the midst of internship applications, but I'm so glad she knew that I was going to be a geropsychologist. As a woman born in the 1920s, she impressed upon me the importance of exercising my right to vote and of not taking my opportunity for a college education for granted. And my maternal grandfather proudly tells everyone that his granddaughter is a "psychologist," which has created some awkward moments in Wal-Mart. When I told him about this dissertation, he said to make sure I say, "don't worry about the mule, just load the wagon!"

My sincerest appreciation and thanks to you all.

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INTRODUCTION

Health literacy, or “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” (Nutbeam, 1998), is an essential component of an individual’s ability to process and utilize health information. High health literacy is positively correlated with treatment adherence (Miller, 2016; Soones et al., 2017), which may lead to a wide variety of improved health outcomes, including better management of chronic health conditions such as diabetes (van der Heide et al., 2014).

Low health literacy is recognized as a national problem within the United States (U.S. Department of Health and Human Services, 2010). A benchmark study conducted by the U.S. Department of Education in 2003 concluded that approximately 12% of U.S. adults have proficient health literacy (Kutner et al., 2006). This proportion decreases with age, and the same study found that 5% of adults between the ages of 65 and 75 have proficient health literacy, while only 1% of adults over 85 have proficient health literacy. Serious economic and social costs are associated with low health literacy, including greater utilization of emergency care, fewer preventive health behaviors, and earlier mortality among older adults with low health literacy compared to those with proficient health literacy (Berkman et al., 2011). This represents a serious challenge to public health, particularly as healthcare providers may frequently overestimate a patient’s health literacy levels (Dickens et al., 2013; Kelly & Haidet, 2007) and therefore be unaware that their patient is at risk for poorer health outcomes.

When evaluating health literacy, it is important to consider Don Nutbeam’s (2000) framework, which describes hierarchical levels of this construct (see Figure 1). This theory suggests that health literacy is made up of various skills and components and should not necessarily be viewed as one discrete ability. Individuals may be high on certain aspects of health literacy but remain limited in others, reflecting the complexity of this concept. However, it is common for researchers to use the overarching term rather than specifying the aspects or components of health literacy that they are considering (Fernandez et al., 2016). Additionally, it has been argued (Nutbeam, 2008) that “overall” health literacy may be difficult to assess, as it seems that no measure as yet exists that can adequately capture the social and cultural factors that contribute to this inherently complex construct.

Health literacy level and educational goal	Content	Outcome	
		Individual benefit	Community/social benefit
Functional health literacy: communication of information	Transmission of factual information on health risks and health services utilization	Improved knowledge of risks and health services, compliance with prescribed actions	Increased participation in population health programs (screening immunization)
Interactive health literacy: development of personal skills	As above and opportunities to develop skills in a supportive environment	Improved capacity to act independently on knowledge, improved motivation and self-confidence	Improved capacity to influence social norms, interact with social groups
Critical health literacy: personal and community empowerment	As above and provision of information on social and economic determinants of health, and opportunities to achieve policy and/or organizational change	Improved individual resilience to social and economic adversity	Improved capacity to act on social and economic determinants of health, improved community empowerment

Figure 1. Nutbeam (2000) Overall Health Literacy Framework.

As described by Nutbeam (2000), the most basic level of health literacy is functional health literacy, which reflects an individual's ability to understand and utilize basic health information. It is important to consider this as a foundation of an individual's overall health literacy, as skills within this domain are necessary to make sound healthcare decisions and successfully implement and adhere to recommended medical treatments and guidelines. For example, functional health literacy is important for understanding and following preventive healthcare recommendations and independently managing medications. A great deal of health literacy research is focused on functional health literacy (Nutbeam, 2008), as this component is highly important for positive treatment outcomes (Berkman et al., 2011) and may be increased through interventions such as patient education (Noordman et al., 2019).

While functional health literacy affects a patient's ability to successfully utilize health information, Nutbeam's (2000) framework also stresses the importance of interactive, or communicative, health literacy, which refers to the social abilities required to communicate with providers and make one's needs known within a medical context. Given the inherent complexity of healthcare systems, this is as equally important as functional health literacy, particularly as patients may be required to coordinate information from multiple sources within these systems. Interactive health literacy may be difficult to measure, particularly as differences in a desire for shared decision-making may act as a confounding factor; for example, older adults may prefer to defer to their physician for treatment suggestions (Cole et al., 2017), but this does not necessarily imply that these individuals do not have the ability to make independent healthcare decisions.

Critical health literacy is the final level within Nutbeam's (2000) model, and this refers to the cognitive skills required to integrate information and make informed and empowered choices regarding healthcare. Skills within this domain allow patients to successfully navigate the

healthcare system while recognizing one's own limitations and the limitations of the system. This may include understanding concepts such as how social determinants of health (i.e., socioeconomic status) apply on an individual level, which allows patients to problem-solve ways in which to compensate for these factors. Ultimately, critical health literacy is considered to be vitally important for overall public health, as acknowledging and addressing concepts such as social determinants of health may result in benefits to society as a whole through reducing disparities.

Palliative Care and Health Literacy

Assessing health literacy can provide information about how a patient comprehends and uses general health information, but this construct can also be applied to more specialized areas, such as mental health literacy (Jorm, 2012) or caregiver health literacy (Yuen et al., 2014). When considering health literacy, palliative care literacy is an important subcomponent to consider, as providers should not assume that those with high health literacy are equally knowledgeable across multiple health domains. Palliative care may include any type of psychological, physical, or spiritual care that promotes quality of life in patients with terminal or life-threatening conditions (World Health Organization [WHO], 2015). On an international level, the WHO (2018) estimates that only 14% of individuals who would benefit from palliative care have accessed these services, and individuals with lower levels of education may be particularly at risk (Kozlov, Cai, et al., 2018). Palliative care covers a wide range of interventions meant to alleviate suffering or manage chronic illnesses rather than provide a cure. Hospice may be the most well-known form of palliative care (Kozlov, McDarby, et al., 2018), but palliative care encompasses a wide range of treatments and non-curative services that may be simultaneously implemented with interventions aimed at providing a cure.

A better understanding of services available through palliative care would likely be beneficial to many individuals, as lack of awareness may prevent those in need from accessing services. Unfortunately, chronic illnesses such as diabetes, cardiovascular disease, and chronic pulmonary obstructive disease, which are typically managed through a palliative approach, are becoming increasingly common within the United States (Ford et al., 2013; Nagheer et al., 2017). Individuals with high health literacy are more likely to have superior treatment outcomes in these cases (Berkman et al., 2011) and are more likely to prefer shared decision-making (Seo et al., 2016), allowing healthcare to be more collaborative and individualized. Identification of low health literacy within these patients allows for interventions to both increase patient-centered care and promote informed decision-making (Noordman et al., 2019), which may be of particular importance in the management of chronic medical conditions. These opportunities to promote understanding and correct misconceptions may be highly beneficial to both patients and their families (Örsal et al., 2019) and may increase provider awareness of any misconceptions. These misconceptions can then be addressed through discussion and education, which has the potential to lead to more positive self-management of health outcomes.

While general health literacy has been consistently linked to education level (i.e., Paasche-Orlow et al., 2005), it should be noted that high levels of education do not necessarily imply adequate levels of palliative care knowledge. For example, in a highly educated sample of Non-Hispanic White (NHW) and Latinx adults in which over 90% of participants had at least some college education, general knowledge of hospice remained low (Kreling et al., 2010). Misconceptions were higher among Latinx participants, indicating that cultural disparities exist independently of education level. Racial disparities in palliative care are well-documented (i.e., Allen et al., 2019; Payne, 2016); for example, African American individuals have been shown to

utilize hospice at a lower rate than their NHW counterparts. This has been attributed to factors such as mistrust of the health system and its providers (Washington et al., 2008), a desire to leave end-of-life decisions in the hands of a higher religious power (Melhado & Bushy, 2011), or lack of culturally competent providers (Allen et al., 2019).

While patients with inadequate palliative care literacy may lack sufficient understanding of what palliative care services entail, misconceptions are also found in physicians and other healthcare providers. This may result in medical professionals being reluctant to discuss services such as hospice with patients due to their own associations between palliative care and death (Wallace, 2016). Many medical schools are attempting to address this by offering increased training opportunities in palliative care, but this training is still limited and may not provide sufficient patient contact hours (Walker et al., 2016). There may be further inequalities within different specialty fields of medicine, as it may be difficult for patients with certain conditions to “qualify” for palliative care access (Boersma et al., 2014), meaning that many providers are unaware of whether or not patients would benefit from referral to palliative services. Unfortunately, misconceptions may be difficult to assess in both providers and patients, as standardized measures of palliative care knowledge (Kozlov, Carpenter, et al., 2017) and attitudes (Perry et al., 2020) are relatively new and are not widely utilized at this time.

Advance Care Planning

It may be difficult for patients from a variety of backgrounds to discuss mortality with providers, but multiple avenues by which individuals can begin considering their end-of-life care preferences exist. In particular, advance care planning is a process by which individuals determine the level of care and intervention that they desire at the end of life (Bischoff et al., 2013). This can take the form of discussing wishes with a relative or healthcare provider, as well

as completing a legal document known as an advance directive that states care preferences and/or names a durable power of attorney for healthcare (Block, Jeon, et al., 2020). Advance care planning is particularly salient at this time given the current COVID-19 (2019 novel coronavirus) pandemic. Since the onset of this pandemic, the number of U.S. adults who have completed an advance directive nominating a healthcare power of attorney has significantly increased (Portz et al., 2020).

Since 1991, the Patient Self-Determination Act has required that certain institutions within the United States (i.e., hospitals) obtain and give information regarding advance directives to patients (Oulton et al., 2015). Despite this, less than half of U.S. adults seen in emergency departments have an advance directive in their medical record, and reported overall completion rates range from below 30% within the general adult population (Oulton et al., 2015) to less than 10% in specific regions (Wickersham et al., 2019). This also varies by setting, as older adults residing in long-term care facilities may complete advance directives at a significantly greater rate (i.e., 60-70%) than their community-dwelling peers (Hold et al., 2019). However, this still leaves a significant proportion of older adults living in skilled nursing homes with chronic medical conditions who may be lacking an advance directive (Kurella Tamura et al., 2017). Unfortunately, the lack of a formal advance directive may result in unwanted interventions, particularly in medical crises, as emergency responders are obligated to default to life-sustaining procedures in the absence of clear documentation (Pearse et al., 2019).

While advance care planning and end-of-life discussions may be difficult in general, a further barrier exists in that it may be challenging for patients and their families to initiate these conversations. As a consequence, these discussions may be postponed until a medical emergency occurs (Bailey et al., 2012). These conversations also require that patients be able to understand

and contemplate complicated or hypothetical medical scenarios, which frequently requires assistance and guidance from healthcare professionals. Despite receiving this guidance from providers, almost half of patients express uncertainty regarding the end-of-life decisions that they have made, and this uncertainty may be higher in ethnic minorities than in NHW individuals (Sudore et al., 2010). However, a Spanish translation of a validated online tool designed to help patients with low health literacy create an advance directive was effective at increasing advance care planning in Spanish-speaking patients (Sudore et al., 2018). This demonstrates that interventions and materials specifically designed for diverse individuals with low health literacy may be effective at reducing disparities in advance directive creation between NHW and minority patients.

Not surprisingly, many patients with limited health literacy may require additional assistance to express their autonomous treatment wishes regarding end-of-life care. These patients are at high risk of defaulting to the wishes of their medical provider, as they may not feel confident or prepared enough to engage in shared decision-making (Muscat et al., 2016). From a physician perspective, shared decision-making regarding end-of-life care may be preferred over complete patient autonomy, as this allows the provider to make recommendations based on the patient's stated goals and preferences (Johnson et al., 2017). This approach may be particularly beneficial for individuals with low health literacy, as this does not require sophisticated medical knowledge or understanding, although it is important that the patient be allowed their desired level of input. It should also be noted that advance care planning is an area in which preferences are likely to change both immediately after diagnosis and during treatment of a serious illness (Sudore & Fried, 2010), and levels of comfort and certainty relating to decisions may fluctuate, making this a dynamic process.

When conducting end-of-life or advance care planning discussions, the provider should be responsive to the patient's need to end the conversation if it becomes too difficult (Barnes et al., 2007). From an ethical perspective (Halli-Tierney et al., 2018), these discussions should take place over multiple occasions, as end-of-life decisions may evolve due to changing circumstances of the patient or changes in prognosis. Additionally, when patients are able to have these discussions with their providers and/or family members, they are less likely to experience unwanted medical interventions (Mack et al., 2010), including lower rates of mechanical ventilation, resuscitation, and intensive care unit (ICU) admissions, as well as experiencing improved quality of life (Wright et al., 2008). These improvements in quality of life may also extend to lower rates of complicated bereavement for caregivers following the death of the patient.

The nature of desired care at the end of life may be influenced by factors such as health literacy (Nouri et al., 2019). Individuals with low health literacy have been shown to prefer more aggressive end-of-life treatment, although this effect was no longer present after viewing a patient education video that showed an individual with advanced dementia (Vollandes et al., 2008). Notably, following only a verbal description of the ramifications of advanced dementia, individuals with low health literacy still preferred more aggressive treatment. This indicates that visual material may be more effective when completing patient education initiatives, as it may allow for greater understanding of the physical changes and consequences associated with the end-of-life process. In addition, individuals with low health literacy may also have more uncertainty regarding end-of-life decision-making (Vollandes et al., 2010). As with treatment preferences, patient education through visual media was able to reduce differences between those

with low and adequate health literacy, leading to more confidence in choices regarding end-of-life care, as well as preference for less aggressive treatment.

While health literacy may influence preferences regarding end-of-life care, death exposure, or an individual's experience with death, may be an equally important factor to consider. Healthcare professionals who are frequently exposed to the dying process due to their occupations may experience negative consequences, including lowered levels of empathy for patients (McFarland et al., 2017) or increased anxiety about the impending nature of one's own death (Harrawood et al., 2009). However, death exposure may have highly individualized effects depending on the person in question, and increased experience with the dying process may be associated with positive outcomes such as greater comfort discussing this topic with patients (Granek et al., 2015). This may have implications for all involved in the dying process, as expectations regarding death may change by virtue of exposure. Family members of terminal cancer patients are more likely to report that their relative received "excellent" care at the end of life when less aggressive treatment options (i.e., longer hospice enrollment and fewer ICU admissions prior to death) were pursued (Wright et al., 2016). As demonstrated by Volandes and colleagues (2008), greater understanding of the dying process may affect an individual's personal care preferences. Observing a loved one's experience with death may affect the individual's desires regarding their own future death, particularly as family members tend to experience similar levels of death anxiety (Freitag & Rauscher, 2017).

In the context of advance care planning, death anxiety may be examined through the lens of Terror Management Theory. Briefly, this theory posits that humans experience tension given their unique ability to be aware of inevitable mortality while still possessing the instinct and desire to remain alive (Greenberg et al., 1986). These conflicting ideas may lead to anxiety, and

this anxiety may be managed through strategies such as religious beliefs and pride in one's contributions to the world that create a sense of immortality of self (Rosenblatt et al., 1989). Unfortunately, even within a medical context, death is not typically viewed as a comfortable topic of discussion in Western culture, and this may contribute to the maintenance of death anxiety (Llewellyn et al., 2016). However, awareness of mortality may also have positive benefits, as this may motivate individuals to engage in healthy behaviors as a means of reducing or managing death anxiety (Goldenberg & Arndt, 2008). Such behaviors may include planning for future care, particularly as exposure to death allows individuals to consider what interventions they would or would not find acceptable at the end of life (Volandes et al., 2008). To our knowledge, it is currently unknown how exposure to death and health literacy may affect an individual's future care preferences.

It is also important to consider that healthcare providers bring their own experiences and biases with death to end-of-life care to discussions with patients and their families (Ho et al., 2016); for example, research has suggested that a physician's own negative expectations and fears regarding death may harm open communication with patients regarding end-of-life decision-making (DeVader & Jeanmonod, 2012; Kvale et al., 1999). This creates the risk of the provider failing to take the values and wishes of the patient into account, or simply avoiding end-of-life discussions (Nelson-Brantley et al., 2020; Weiner & Cole, 2004).

From an international perspective, desired end-of-life care and discussions regarding this topic can vary between different cultural groups. As global immigration increases, providers may be increasingly called upon to treat patients from a variety of cultural backgrounds. While a model of shared decision-making may be viewed as ideal within Western societies (Legare et al., 2011), this may not be the preferred method of decision-making within all cultures (Hawley &

Morris, 2017; Romain & Sprung, 2014). There is no universal standard of what makes a “good death,” and there are cultural differences regarding how involved patients, families, and communities would like to be in the end-of-life process (Zaman et al., 2017). Despite this, common themes relating to a good death that are found throughout the world include the desire to minimize pain and pass away at home (Kastbom et al., 2017).

Physician-Assisted Death

When considering end-of-life preferences and comfort with death, the option to voluntarily and autonomously choose to hasten one’s own death with the assistance of the medical community is increasing in availability in many jurisdictions. Terminology regarding hastening the end of life may vary, and terms such as physician-assisted death (PAD), medical aid in dying, physician-assisted suicide, euthanasia, and death with dignity are frequently used. Hendry and colleagues (2012) provide a review on attitudes towards PAD from a global perspective, taking multiple viewpoints into account. There is a great deal of controversy surrounding terminology, particularly as terms such as “suicide” frequently have cultural or religious implications (Chochinov, 2016; Miccinesi et al., 2005). There may also be legal connotations associated with choice of terminology, as “euthanasia” may refer to the active ending of a patient’s life by a medical professional (Emanuel et al., 2016). This is an important distinction, as multiple jurisdictions, including several U.S. states and Switzerland, protect PAD but not euthanasia. Some countries, such as Belgium (Chambaere et al., 2010), may allow euthanasia in circumstances where the patient is not able to provide direct consent. This may be due to circumstances such as dementia and usually involves consultation from family members, and it is becoming increasingly common for euthanasia to be utilized outside of the United States under strict regulations (Dierickx et al., 2020).

In 1997, Oregon became the first North American jurisdiction to legalize PAD through the Oregon Death with Dignity Act (Death with Dignity, 2020). Within the United States, PAD is currently legal in the jurisdictions of California, Colorado, Hawaii, Maine, New Jersey, Oregon, Vermont, Washington D.C., and Washington. Montana does not have specific legislation that allows PAD, but physicians who provide hastened death to terminally ill patients cannot be prosecuted under the Rights of the Terminally Ill Act (*Baxter v. Montana*, 2009). In addition to the named states, multiple other jurisdictions were expected to hear bills regarding PAD in 2020; unfortunately, many of these hearings have been postponed due to the COVID-19 pandemic.

While PAD is currently an option in multiple jurisdictions, it should be noted that laws relating to medical aid in dying are subject to change; for example, California rescinded the option to pursue PAD in May of 2018 (Scutti, 2018), although it was later reinstated in January of 2020 (Death with Dignity, 2020). Currently, all U.S. jurisdictions that allow PAD require that the patient be at least 18 years of age, be terminally ill, and possess the legal capacity to make medical decisions (Emanuel et al., 2016). In all cases of patients requesting medical aid in dying, respect for autonomy needs to be balanced with the protection of individual rights, particularly among disadvantaged or stigmatized groups (Schwartz & Lutfiyya, 2009).

While attitudes may be shifting within the United States, multiple groups and individuals remain opposed to PAD. Many of these objections may be understood through consideration of historical and social contexts, particularly when taking cultural differences into account. Ultimately, PAD will create an ethical dilemma for many individuals, including healthcare professionals who are willing to counsel patients regarding this decision and prescribe lethal medications, typically barbiturates (Shankaran et al., 2017), with the knowledge that their patient

may choose to end their own life (Craig & Dzeng, 2018). Many cases involving medical aid in dying are complex, and they must ultimately be viewed as a balance of beneficence and nonmaleficence, as well as an individual's right to autonomy and dignity.

Need for Study and Ethical Considerations

Study One focused on functional health literacy and utilized data that is being collected as part of an ongoing project taking place in The University of Alabama Geriatrics Clinic. Patients in this clinic whose performance on emotional health screening measures is indicative of clinically significant symptomatology are directed to an appropriate referral source (i.e., The University of Alabama Geropsychology Clinic). This information, as well as the results of cognitive screeners, is given to a board-certified, licensed geriatrician, who then provides feedback and any necessary medical care.

Data collection for Studies Two and Three built upon the findings of Study One regarding functional health literacy and took place exclusively through the Amazon Mechanical Turk (MTurk) platform. These studies involved potentially distressing information, including questions about death exposure and future end-of-life care preferences. Upon study completion, participants were provided with a debriefing form that included national referral sources, such as the National Suicide Hotline. In addition, information regarding the creation of an advance directive was also provided.

Taken together, the current studies have the potential to significantly add to the health literacy and end-of-life literature. All three studies have both clinical and research implications, as they build incrementally by including variable of interest (functional health literacy in Study One, palliative care knowledge in Study Two, and attitudes toward physician-assisted death in Study Three) and may increase understanding of how individuals approach advance care

planning and decisions regarding the end of life. Health literacy is increasingly measured in primary and specialized care settings (Weiss et al., 2005), and this is a particularly important construct to understand when considering how individuals choose to make decisions about the care received at the end of life. This is a highly personal and individualized decision (Zaman et al., 2017), and increased knowledge in this area will potentially help patients and their families to autonomously choose a “good death.”

STUDY ONE OVERVIEW

Despite the fact that health literacy is an important construct to measure and understand, multiple authors (Baker, 2006; Rudd et al., 2007) have suggested that the field is currently lacking a measure able to comprehensively assess health literacy. Commonly used measures, such as the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993), may be estimating levels of basic literacy, which, while essential for and related to health literacy (DeWalt et al., 2004), should not be considered as equivalent (Kickbush, 2001; Nutbeam, 2008). There may also be a lack of focus on the social and cultural aspects of health literacy in many measures, and this is a critically important domain that should not be ignored (Ishikawa & Kiuchi, 2010; Nutbeam, 2000), particularly as patients with low health literacy may have poorer communication with physicians (Ishikawa et al., 2009). Older adults may be especially vulnerable to this, as they may be more likely to default to a paternalistic model of medical decision-making in which they defer to the physician rather than express their own needs and desires regarding treatment (Cole et al., 2017).

Thorough assessment of patient health literacy has long been acknowledged as difficult in healthcare settings, particularly when working with older adults (Brooks et al., 2020). This may be due to factors such as a lack of reliable screening measures, provider discomfort, and time barriers. Despite this difficulty, there are numerous benefits to assessing health literacy, including the opportunity to provide health education and other interventions for patients with limited health literacy. In addition, patients may engage in the use of coping mechanisms to

disguise low health literacy from providers, making the use or inclusion of objective measures preferable (Shealy & Threatt, 2016). Even patients with high health literacy appear to benefit from having medical information presented in a simplified fashion (Meppelink et al., 2015), and this may be due to the inherent complexity of the medical system (Shealy & Threatt, 2016). In a primary care setting, patients who undergo health literacy interventions report more satisfaction with both their care and physician (Örsal et al., 2019), and this may result in both health and economic benefits.

When assessing health literacy, it is important to distinguish between the separate components of functional and subjective health literacy. Subjective health literacy is calculated based on an individual's report regarding their own perception of their health literacy and may also provide important information about self-efficacy (Schultz & Nakamoto, 2013) and confidence in communicative abilities (Nutbeam, 2000). In contrast, functional health literacy requires individuals to complete tasks that can be scored as objectively correct or incorrect (Heijmans et al., 2015); for example, patients may be asked to read lists of medical words or complete calculations related to health behaviors. It may be vital to use measures of functional health literacy in an older adult population, as health literacy skills that utilize fluid cognition may be particularly vulnerable to age-related degeneration (Kobayashi et al., 2016). In addition, health literacy may decrease in the context of memory decline (Geboers et al., 2018). Given the potential consequences of overestimating health literacy, this represents a serious barrier to patient care, as low functional health literacy may result in unsafe behaviors such as difficulty with medication management (Soones et al., 2017).

The aim of Study One was to assess both subjective and functional health literacy in older adults presenting at the Geriatrics Clinic based in The University of Alabama (UA) University Medical Center (UMC). The UA Geriatrics Clinic is an interdisciplinary setting in which older adults presenting in an outpatient primary care practice receive comprehensive interdisciplinary medical care. The interprofessional team consists of medicine, pharmacy, psychology, and social work, and the shared goal is to provide organized collaborative care to maximize patient functioning and well-being. Beginning in 2012, all patients have received annual cognitive and emotional health (depression, anxiety) screeners, with results entered into their electronic medical record. As of 2014, if patients provide informed consent, they also complete additional screeners of health literacy, psychological flexibility, and substance use, again on an annual basis. Data collection has been continuously approved by the UA Institutional Review Board (IRB) since 2014 (14-005-ME-R4).

As overall health literacy as defined by Nutbeam's (2000) framework requires the development and utilization of multiple skills, an important first step when considering health literacy is the evaluation of an individual's basic functional ability to utilize health information. Functional health literacy acts as a building block for other components of health literacy, such as self-empowerment and communicative skills, and low functional health literacy may prevent patients from being able to manage their healthcare effectively. This construct may be of particular importance when working with older adults, as functional health literacy may provide relevant information regarding cognitive status (Kobayashi et al., 2016). As a screener of cognitive status is collected annually for all patients presenting in Geriatrics Clinic, monitoring this information along with functional health literacy may provide important information regarding overall cognitive functioning relevant for living independently. For example, a decline

in the domain of functional health literacy in an individual who has previously performed well on such tasks may be an indicator that fluid problem-solving skills are potentially impaired.

At the onset of data collection, health literacy was measured using Chew, Bradley, and Boyko's (2004) 8-item screener of subjective health literacy. Possible scores range from 8 to 40, with higher scores indicating greater self-reported health literacy. The measure includes questions such as "How confident are you filling out medical forms by yourself?" Health literacy scores are then categorized as "adequate," "marginal," or "inadequate." As of 2017, approximately 81% of the patients screened on 221 occasions reported adequate health literacy, while 16% fell within the marginal range, and 3% fell within the inadequate range. This is in direct contrast to results from a 2003 study (Kutner et al., 2006), which found that only a small proportion of older adults have proficient health literacy as assessed by the National Assessment of Adult Literacy survey. Given this discrepancy, concerns were raised that the utilized measure was not adequately representative of health literacy within the Geriatrics Clinic patient population. As health literacy is a broad construct with multiple components (Nutbeam, 2000), it was of particular concern that the measure developed by Chew and colleagues (2004) was assessing interactive health literacy and self-efficacy (Nutbeam, 2000) rather than providing a true objective measure of basic functional health abilities. While it is important to be aware of a patient's level of self-efficacy, low functional health literacy may contribute to potentially dangerous yet correctable health behaviors, such as poor medication management (Soones et al., 2017) or lack of adherence to preventive care recommendations (Chesser et al., 2016), and these issues are of particular relevance in a primary care clinic.

Based on these concerns, it is important to note that there may be significant differences between Geriatrics Clinic patients' self-reported health literacy and their basic, or functional,

health literacy skills. Again, even though self-efficacy and subjective perceptions of health literacy are important constructs to assess, it does not preclude patients with high levels of empowerment from confidently engaging in dangerous health behaviors, particularly if they believe that they are following medical advice accurately. Awareness of this discrepancy may be crucial to identify patients who are at risk to fall into this category, as interventions (Noordman et al., 2019) such as providing education and having individuals repeat back information in their own words may be highly effective.

As an additional example of the lack of equivalency between the constructs of functional and subjective health literacy, it has been demonstrated at an international level that patient self-reports of health literacy using Chew and colleagues' (2004) screener do not necessarily correlate with performance on more objective measures of health literacy (Mantwill et al., 2018). Given this discrepancy, the Newest Vital Sign (NVS; Weiss et al., 2005) was added to the Geriatrics Clinic assessment battery in January of 2018 as a measure of functional health literacy. This additional information was expected to provide more extensive information regarding patients' ability to use health information, and this inclusion was made with the overarching goal of providing more comprehensive patient care. As basic functional health literacy is crucial to acting upon health information and interacting with the healthcare system (Nutbeam, 2000), it is an important first step to establish patients' abilities within this domain prior to understanding their social and interactive confidence and abilities when subsequently using this information.

A final topic of interest in this sample was the relationship between emotional health and both subjective and functional health literacy. As with cognitive status, self-reported symptoms

of depression and anxiety are assessed annually within the Geriatrics Clinic, making it possible to monitor these associations. Prior research has demonstrated that individuals with inadequate health literacy are more likely to experience mental health symptomatology compared to those with adequate health literacy (Wolf et al., 2010). Multiple mechanisms for this relationship have been proposed, including the positive correlation between health literacy and independence in daily activities (McDougall et al., 2012), as well as the hypothesis that individuals with low health literacy are less likely to recognize symptoms of psychopathology and subsequently seek treatment (Kim et al., 2015). There is a growing body of literature that suggests that low health literacy may be linked with symptoms of depression (i.e., Zhou et al., 2019) and anxiety (i.e., Kampouroglou et al., 2020), suggesting that this an area that requires further exploration.

Study One Hypotheses

Based on prior research (Mantwill et al., 2018), it was hypothesized that there would not be a significant positive correlation ($p > .05$) between functional performance on the NVS and self-reported health literacy. Prior findings have shown that a single-item version of Chew and colleagues' (2004) screener correlates negatively with performance on the NVS (Kiechle et al., 2015). Additionally, as discussed above, self-reported health literacy may not be reflective of functional health literacy and the ability to apply this information meaningfully (Mantwill et al., 2018).

It was also hypothesized that both low functional and subjective health literacy would be associated with higher levels of self-reported depression and anxiety. It has been demonstrated that individuals with low health literacy are more at risk to experience clinically significant symptomatology due to a lack of recognition of symptoms relevant to mental health, which therefore results in a failure to seek treatment (Kim et al., 2015). Finally, both subjective and

functional health literacy were hypothesized to be positively correlated with cognitive functioning, as both of these domains require the ability to successfully manipulate and utilize complex information (Geboers et al., 2018; Kobayashi et al., 2016). This is consistent with prior research on this topic.

The current study adds to the literature by examining the relationship between self-reported and functional health literacy in an understudied population. While patients with severe cognitive deficits are excluded from this research study, only 27.9% (n = 274) of total Geriatrics Clinic patients as of April 2020 scored within the cognitively intact range on initial cognitive screeners. Differences between self-reported and functional health literacy may be particularly important to measure within a population in which cognitive impairment is prevalent, as awareness of discrepancies between these two aspects of health literacy may impact future medical treatment and care.

Study One Methods

Study One Participants and Procedure

Self-reported and functional health literacy data were collected from 102 patients presenting at the UMC Geriatrics Clinic for primary care appointments between January 2018 and April 2020. Data collection was suspended in April 2020 in response to UA's move to limited business operations due to the COVID-19 pandemic. Participants were comprised of all presenting patients who agreed to take part in the study and were able to provide informed consent consistent with UA IRB guidelines (i.e., the patient was able to display adequate understanding, appreciation, and reasoning regarding participation). At the time of initial visit, a clinical geropsychology graduate student reviewed study information with patients above a

certain cognitive threshold (as measured by clinical judgment or a score equal to or greater than 11 on one of the cognitive screeners discussed in the Study One Measures section) and answered any questions the individual expressed regarding the research. If patients indicated interest in participating, informed consent was reviewed, and participants were presented with additional behavioral health assessments, including health literacy measures. Questions were read aloud to patients by the clinical geropsychology student to ensure that poor eyesight or low levels of basic literacy did not interfere with understanding. Response cards were also provided to patients to facilitate understanding and display response options to specific survey questions. While these data are collected on an annual basis, for the present study, only the first time point using the measures described below was considered for analyses.

Measures

Basic demographic information was collected for all patients enrolled in this study. This includes age, gender, race/ethnicity, and urban/rural residency status.

Health literacy. Functional health literacy was assessed using the NVS (Weiss et al., 2005). This measure was designed for use in a primary care setting, and individuals were presented with an ice cream label containing nutrition information. They were then asked six questions regarding their ability to understand and interpret this information. Scores between 0 and 1 indicate a high likelihood of limited health literacy; scores between 2 and 3 indicate the possibility of limited health literacy; and scores greater than 4 indicate adequate health literacy. The NVS is highly useful as a screening tool, particularly as it may not cause patients with low health literacy to feel ashamed or inadequate (VanGeest et al., 2010). The NVS is designed to be administered in approximately three minutes, although previous research (Patel et al., 2011) has

found that administration may be extended to a mean time of 11 minutes when working with minority older adults.

In addition to the NVS, participants completed a three-item measure of self-reported health literacy developed by Chew and colleagues (2004) to assess subjective health literacy. Of the original eight-item brief health literacy screener given to Geriatrics Clinic patients prior to January 2018, these three embedded questions have been demonstrated to identify patients with limited health literacy as adequately as the original eight-item version (Chew et al., 2008). It was considered important to continue screening of subjective health literacy, as this allows for both continuity of data collection and the assessment of patient self-efficacy. Using a 5-point Likert scale, patients rated their confidence in filling out medical forms by themselves, how often they have someone help them read hospital materials, and how often they experience comprehension problems when reading medical materials. The three items were then averaged, and a score of 1-3 is classified as reflective of limited subjective health literacy, while a score of 3-5 is reflective of adequate subjective health literacy (Kiechle et al., 2015). Scores were also compared to clinic health literacy data collected using the previously utilized 8-question version.

Cognitive status. To measure cognitive status, patients were randomly given either the St. Louis University Mental Status exam (SLUMS; Tariq et al., 2006) or the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005). Scores on both of these measures range from 0-30 and may be classified as indicative of intact functioning, mild cognitive impairment, or dementia. On both measures, scores of 26 and above are indicative of intact cognition.

Emotional health. Symptoms of depression were assessed using the 15-item Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986). Patients respond to these items with forced yes/no options, and scores range from 0-15. Scores of 5 or greater are suggestive of clinically significant symptoms of depression.

Symptoms of anxiety were assessed using the 5-item Geriatric Anxiety Inventory – Short Form (GAI; Pachana et al., 2007). As with the GDS, patients answer yes/no questions about their subjective experience of anxiety. Scores range from 0-5, and scores of 3 or greater are suggestive of clinically significant symptoms of anxiety.

Study One Data Analysis

The relationship between patient performance on the two health literacy measures was analyzed using bivariate Pearson correlations. Correlations were also calculated between both functional and subjective health literacy and symptoms of depression, anxiety, and cognitive status. Differences in both types of health literacy between various groups (i.e., gender or race/ethnicity) were analyzed through *t*-tests. Scores of subjective health literacy using the 8-item and 3-item self-report measures were compared by calculating z-scores and performing within-subjects *t*-tests. Finally, between-group analyses based on NVS score were conducted using ANOVAs.

Study One Results

Patients were community-dwelling older adults over the age of 50 ($M = 73.17$, $SD = 8.30$), and the majority of these individuals resided in West Alabama. The sample was predominantly female (75.5%) and non-Hispanic White (NHW; 93.1%). Approximately 10% of

patients resided in rural counties within Alabama or Mississippi. See Table 1 for further information regarding participant demographics.

Table 1. Demographic variables of Geriatrics Clinic patients ($n = 102$).

Measure	
Age, $M(SD)$	73.17 (8.30)
Gender, $n (%)$	
Female	77 (75.5)
Race/ethnicity, $n (%)$	
African American	6 (5.9)
Urban/Rural Status, $n (%)$	
Urban	36 (90)

The means, standard deviations, and possible ranges of variables of interest are included in Table 2, and bivariate correlations are included in Table 3.

Table 2. Descriptives for Geriatrics Clinic variables ($n = 102$).

Measure	M(SD)	Possible Range
Functional Health Literacy (NVS)	2.99 (2.07)	0-6
Subjective Health Literacy (3-item)	4.28 (0.94)	1-5
Cognitive Functioning	23.32 (4.34)	0-30
Depression	3.37 (3.51)	0-15
Anxiety	1.40 (1.68)	0-5

Table 3. Bivariate correlations of Geriatrics Clinic variables ($n = 102$).

Construct	1	2	3	4	5
1. Functional Health Literacy (NVS)	1.00				
2. Subjective Health Literacy (3-item)	.47***	1.00			
3. Cognitive Functioning	.58***	.43***	1.00		
4. Depression	-.15	.44***	-.19*	1.00	
5. Anxiety	-.17	-.45***	-.19*	.72***	1.00

*** $p < .001$, * $p < .05$

When assessing subjective health literacy, 90.8% ($n = 89$) of participants reported that they had adequate health literacy ($M = 4.28$, $SD = 0.94$). There was a significant negative association between age and subjective health literacy ($r = -.29$, $p < .01$), although subjective health literacy did not differ significantly by participant gender. Non-Hispanic White participants ($M = 4.34$, $SD = 0.88$) reported higher levels of subjective health literacy compared to African American participants ($M = 3.56$, $SD = 1.47$), $t(95) = 2.01$, $p < .05$. However, these results should be interpreted with caution given the low number of African American patients in the current sample.

In contrast, when assessing functional health literacy, only 44.1% ($n = 45$) of patients scored within the adequate range ($M = 2.99$, $SD = 2.07$), while 23.5% ($n = 24$) scored within the possibly limited range, and 32.4% ($n = 33$) scored within the highly limited range. There was a significant negative association between age and functional health literacy ($r = -.45$, $p < .001$), indicating that younger patients performed better on the NVS than older patients. Female participants ($M = 3.22$, $SD = 2.04$) demonstrated higher functional health literacy than male participants ($M = 2.28$, $SD = 2.01$), $t(100) = 2.01$, $p < .05$. As seen with subjective health literacy, NHW participants ($M = 3.04$, $SD = 2.07$) scored higher on a measure of functional health literacy than African American participants ($M = 1.67$, $SD = 1.21$), $t(7.008) = 2.56$, $p < .05$, although these results regarding racial/ethnic disparities should again be interpreted with caution.

There was a significant positive correlation between functional and subjective health literacy ($r = .47$, $p < .001$), which does not support the study hypothesis. As Levene's test was significant ($p < .001$), the assumption of equal variances in this sample was not met. A one-way Welch's ANOVA was conducted to analyze differences in subjective health literacy by NVS

group, and a significant main effect was found, $F(2, 40.59) = 15.71, p < .001$. Post-hoc analysis using the Games-Howell test demonstrated significant differences in subjective health literacy between participants in the adequate functional health literacy group compared to both groups of participants with limited health literacy. See Table 4 for further details.

Table 4. Subjective Health Literacy by NVS Category (n = 102).

NVS Category	<i>n</i>	Subjective Health Literacy <i>M(SD)</i>
Adequate	44	4.77 (0.44)***
Possibly Limited	22	4.11 (0.85)
Highly Limited	32	3.73 (1.15)

*** $p < .001$

In the selected sample, 27.2% of participants scored within the cognitively intact range, which is consistent with the overall dataset. Unsurprisingly, there was a significant positive correlation between cognitive status and both functional ($r = .58, p < .001$) and subjective ($r = .48, p < .001$) health literacy, indicating that more intact patients were better able to utilize and appraise their ability to understand health information.

Reported symptoms of anxiety in this sample were generally low ($M = 1.40, SD = 1.68$), although 26.4% ($n = 24$) of patients endorsed clinically significant symptoms of anxiety on the GAI. Similarly, reported symptoms of depression were also low ($M = 3.37, SD = 3.51$), with 26.1% ($n = 24$) of patients endorsing clinically significant symptoms of depression on the GDS. While functional health literacy was not significantly associated with symptoms of depression or anxiety, subjective health literacy was negatively correlated with both depression ($r = -.44, p < .001$) and anxiety ($r = -.45, p < .001$). ANOVAs comparing depression and anxiety scores by functional health literacy group as determined by the NVS were not significant.

Of note, 38 patients who completed the 8-item Chew, Bradley, & Boyko (2004) screener completed the shortened 3-item version at a follow-up visit. While there was a significant association ($r = .62, p < .001$) between the two questionnaires, this correlation is much lower than expected given that subjective health literacy was expected to remain relatively stable in the short period of time between assessments. To further examine this, subjective health literacy scores were converted to z-scores, and a within-subjects t -test was conducted to assess for longitudinal changes. This was not significant ($t(37) = 1.32, p > .05$), indicating that subjective health literacy scores did not change significantly between measure administration. However, it must be noted that only 38 subjects completed both versions of this measure, and this sample size is unlikely to increase given that it has been almost three years since the discontinuation of the 8-item version.

Study One Discussion

The results of this study highlight the importance of measuring both subjective and functional health literacy, as discrepancies were found between these two constructs in the current sample. While Chew, Bradley, and Boyko's (2004; 2008) screeners may provide useful information about a patient's level of self-efficacy and their own perception of their health literacy (Mantwill et al., 2018; Nutbeam, 2000), this does not necessarily provide information regarding their functional or objective health literacy. Awareness of this discrepancy is vital for patient care, as this may allow medical professionals to provide additional assistance to ensure that patients are in fact able to comply with treatment recommendations. For example, early identification of low functional health literacy may result in further evaluation and guidance that will ensure that patients are engaging in positive health behaviors, including taking medications

correctly and meeting guidelines for preventive recommendations such as annual screenings and vaccinations.

The main study hypothesis that functional and subjective health literacy would not be significantly correlated was not supported, but differences between these two constructs were still observed. Of note, approximately 90% of patients in the Geriatrics Clinic sample reported adequate subjective health literacy, while less than 50% were able to demonstrate adequate functional health literacy on a more objective measure. Results of functional health literacy assessments were more consistent with national data suggesting that older adults are at risk for low health literacy (Kutner et al., 2006; Wannasirikul et al., 2016), and the discrepancy between subjective and functional health literacy in the current sample demonstrates the importance of considering the many facets of this construct when conducting assessments (Shealy & Threatt, 2016). This highlights the importance of establishing functional levels of health literacy before assessing for self-efficacy or empowerment (Nutbeam, 2000), and Studies Two and Three will attempt to demonstrate that this may have significant implications when considering choices and plans regarding future care. It should also be noted that providing healthcare materials at a reading and graphical level that is accessible to most U.S. adults promotes general understanding and has been demonstrated to be acceptable to patients with high health literacy (Meppelink et al., 2015).

When examining differences in subjective health literacy across NVS categories, unequal variances were found between groups, as there was greater variability within individuals who demonstrated highly limited functional health literacy when compared to individuals with adequate functional health literacy. It is possible that participants with lower health literacy may have lower awareness regarding their actual functional abilities compared to participants with

adequate health literacy. Limited patient insight regarding health literacy has been demonstrated by prior research (Paasche-Orlow & Wolf, 2007), and insight may in fact be poorer in those with low health literacy (Diviani et al., 2016). This may partially explain why functional and subjective health literacy were significantly correlated in the current sample, as individuals with high functional health literacy may have a more realistic appraisal of their own abilities. Identifying patients with low health literacy and limited insight may allow them to benefit from interventions aimed at increasing health literacy and positive health behaviors (Noordman et al., 2019), as well as potentially allowing them to be connected with available community resources (i.e., home health or medication management services).

Given the longitudinal nature of the parent study, data were available for 38 participants who completed both the 8-item version of Chew, Bradley, & Boyko's (2004) screener and the shortened 3-item version. While the two versions were significantly correlated, this correlation was weaker than expected and calls into question the reliability of these screening measures in the Geriatrics Clinic population. While changes in health literacy may be an early indicator of cognitive decline (Kobayashi et al., 2016; Yu et al., 2017), significant changes in cognitive status during the same time period were not observed in the current sample. It is therefore unlikely that cognitive decline was a significant contributory factor to the modest correlation between self-reported health literacy at two separate time points. Given that other constructs may be involved in subjective health literacy, including self-efficacy and emotional health factors, it is possible that this correlation is reflective of changes in mental health, self-efficacy, or empowerment rather than changes in cognition or baseline functional health literacy.

Of note, functional health literacy was significantly higher in both NHW and female participants compared to African American and male participants. Subjective health literacy was

also significantly higher in NHW participants. While the current sample is predominantly female and NHW, social determinants of health are important to consider, as they may contribute to observed racial/ethnic discrepancies in health literacy (Adler et al., 2016). This may include factors such as trust in the healthcare system, education, and socioeconomic status, which may determine or influence an individual's ability to access medical care (Muvuka et al., 2020). African American patients may be at high risk to experience many of these barriers, particularly as the majority of individuals seen in Geriatrics Clinic are residents of Alabama and Mississippi. Minority older adults who were raised in this region have likely experienced decades of systemic oppression and inequality given the cultural and historic context (Zhang et al., 2016). Assessment of functional and subjective health literacy may be particularly important in this setting, as health literacy has been shown to mediate factors such as socioeconomic status, education, and access to health information in minority adults (Hovick et al., 2014).

The majority of older adults who engage in routine mental health screening through primary care find this service beneficial, and this routine screening may help to reduce stigma surrounding mental health treatment and allow for the provision of more optimal patient care (Samuels et al., 2015). In the current sample, increased symptoms of depression and anxiety were significantly associated with lower self-reported subjective health literacy. While prior research has demonstrated that individuals with low health literacy may be less likely to recognize associated symptoms and seek treatment (Kim et al., 2015), this relationship was not found with functional health literacy. As symptoms of depression and anxiety were only associated with subjective health literacy in the current study, it is possible that symptoms are having a negative impact on self-efficacy and empowerment rather than the ability to complete functional tasks in a medical context. These patients may be more at risk of passive engagement

with the healthcare system and subsequent poorer health-related outcomes (Paasche-Orlow & Wolf, 2007). This was demonstrated in a nationally-representative sample of older adults, as individuals with low subjective health literacy were less likely to engage in recommended preventive health behaviors such as flu vaccination or mammogram (Fernandez et al., 2016).

Interventions that address low health literacy may cause a subsequent increase in both self-efficacy and health (Osborn et al., 2011), and interventions that are targeted at individuals with low health literacy do not appear to have negative consequences when also presented to those with high health literacy (Meppelink et al., 2015). Such interventions may be beneficial to Geriatrics Clinic patients who report high subjective health literacy yet appear to have limited functional health literacy, as awareness of this discrepancy may allow providers to spend additional time ensuring understanding of and compliance with medical information. Similarly, patients with high functional and low subjective health literacy may benefit from interventions aimed at increasing self-efficacy or health empowerment. This may be particularly true for individuals whose subjective health literacy may be negatively impacted by treatable mental health factors such as depression or anxiety.

Study One Limitations

A limitation of the current study is the lack of data regarding the education level of participants. While patients are theoretically asked for their highest level of education when given a cognitive screener, this data is not currently recorded for analyses. Given the relationship between education and health literacy, it would be highly beneficial to have this information available to provide contextual information regarding participant scores on measures of both subjective and functional health literacy. For example, if a highly educated patient scores low on both measures, this may be more concerning in terms of low perceived self-efficacy or changes

in cognition compared to a patient with less education who achieves the same scores. To address this in the future, an IRB modification has been submitted. Additionally, since the introduction of the NVS to the Geriatrics Clinic battery, the original recommendations have been revised (Weiss, 2018) to allow for the use of paper/pencil and/or a calculator in test administration. While this is not anticipated to impact scores, this modification may allow for faster administration and greater patient comfort in the future.

A final limitation is the small number of participants screened at this time. While 102 patients were recruited over a two-year period, potential subjects are limited to the number of individuals who receive primary care in the UA UMC Geriatrics Clinic, and space and physician availability by necessity define clinic capacity. Trends in the data will continue to be monitored in the future; in particular, the relationship between subjective and functional health literacy remains of interest given the greater variability in subjective health literacy in those with low functional health literacy. Additionally, as the parent study is a longitudinal data set, future analyses may examine how changes in health literacy are associated with changes in other study variables, including cognitive status, depression, and anxiety.

Study One Conclusions

The results of Study One demonstrate that functional and subjective health literacy, while related, cannot be viewed as equal constructs within a community-dwelling sample of older adults. Self-reported subjective health literacy was significantly higher in these individuals than their functional ability to use presented health information correctly, indicating that perceived health literacy skills were higher than actual skills. Knowledge of these two constructs provides information regarding an individual's self-efficacy, as well as their functional health literacy, and early identification of patients with a discrepancy between these two components may allow for

guidance from providers to help promote adherence to recommended health behaviors.

Ultimately, it is hoped that such assistance will allow community-dwelling older adults to live healthier lifestyles and increase their quality of life through improved physical and emotional functioning.

Study One established the importance of assessing functional health literacy in community-dwelling adults, as patient self-reports regarding their own health literacy does not always appear to be accurate. In addition to providing information regarding how a patient is able to use health information, functional health literacy also appears to influence how individuals make decisions regarding medical care and procedures. For example, patients with low functional health literacy may be less likely to engage in preventive health behaviors, including compliance with vaccinations or annual screenings (Fernandez et al., 2016). This may also extend to preparation for future care at the end of life, which is recognized as a critically important domain of preventive care given the high emotional and financial costs associated with receiving unwanted interventions at the end of life (Goldberg et al., 2019; Mack et al., 2010).

An important next step after establishing functional health literacy is to determine how this impacts medical decision-making regarding future care, as individuals with low health literacy have been shown to have a poorer understanding of the ramifications of end-of-life care choices compared to those with adequate health literacy (Vollandes et al., 2008). Thus, the aim of Study Two is to examine how functional health literacy interacts with other constructs to influence engagement in advance care planning and determining desired interventions at the end of life. As demonstrated in Study One, identification of patients with low functional health literacy is easily achievable through brief screeners, and further understanding of how this

construct influences advance care planning may allow vulnerable patients to receive assistance from providers to make choices most consistent with their values and preferences.

STUDY TWO OVERVIEW

Advance directives allow patients a degree of autonomy in planning future care, particularly if they find themselves in a situation in which it is not easy to communicate their current wishes (Reinhardt et al., 2015). This is highly significant, as it has been demonstrated that healthcare surrogates designated by older adults are frequently unable to accurately identify the patient's desired treatment preferences should they experience a medical event that results in a lack of medical decision-making capacity (Bravo et al., 2018). In addition, healthcare agents may overestimate the negative impact of chronic illness on the patient's quality of life (Curtin et al., 2019), creating further barriers to receiving desired care. However, creation of an advance directive may help to negate this discrepancy and allow patients to receive requested interventions at the end of life.

Older adults with higher health literacy are more likely to have prepared a legally-recognized advance directive, but overall preparation of this document remains low (Oulton et al., 2015). Functional health literacy may be particularly important to consider in this population, as the health literacy of older adults may be a better predictor of the creation of an advance directive than experience with advance care planning (Nouri et al., 2019). As demonstrated in Study One, discrepancies may exist between an older adult's perception of their health literacy and more objective levels of this construct, making it vital to measure functional health literacy.

Study Two assessed the relationship between health literacy, death exposure, and advance care planning choices in a diverse group of community-dwelling participants. When

preparing for future care, being aware of vulnerabilities has been shown to motivate individuals to begin considering and making concrete plans (Sörensen & Pinquart, 2000), such as creating a formal advance directive or engaging in discussions with medical professionals. Routine screening for health literacy may help healthcare providers identify low functional health literacy and discuss this as a vulnerability with patients, as improving this most basic level of health literacy (Nutbeam, 2000) may allow individuals to become more independent and empowered regarding future healthcare choices. This is an important area of study, as higher levels of health literacy may increase an individual's comfort levels when engaging in advance care planning (Nouri et al., 2019), making it important to accurately assess health literacy.

Advance care planning is associated with multiple positive public health outcomes, including fewer unwanted medical interventions (Mack et al., 2010) and higher quality of life (Wen et al., 2019), although overall engagement with advance care planning within the United States is low (Oulton et al., 2015; Pearse et al., 2019). Individuals with low health literacy may be particularly vulnerable, as barriers such as limited provider time and high emotional burden may contribute to difficulties understanding information and making medical decisions (Roodbeen et al., 2020). Given this vulnerability, it is particularly important to engage in advance care planning prior to the need to make urgent medical decisions.

In addition to those with low health literacy, older adults in general are also at risk to lack an advance directive or fail to engage in formal advance care planning, and minority community-dwelling older adults may be particularly vulnerable (Jeong et al., 2015). Of note, while racial/ethnic disparities continue to exist between NHW and African American older adults regarding possession of an advance directive, this disparity may be decreasing within the United States (Koss & Baker, 2017). These discrepancies may exist due to unique social and historical

factors, particularly for African American older adults in the Deep South, and informal discussions may be a more effective form of advance care planning for these individuals (Sanders et al., 2016). However, interventions aimed at increasing education and advance care planning engagement for minority older adults have been shown to be effective (Sudore et al., 2018), and their utilization may be highly beneficial in decreasing observed disparities.

Multiple jurisdictions have documents by which patients can complete advance directives that are both standardized and may be placed in medical records as legally-binding documents within that jurisdiction. These documents, which may contain medical orders for goals of care or “living wills,” have been shown to enhance desirability of treatment, in addition to reducing medical costs for unwanted interventions and improving quality of life (Bischoff et al., 2013). This allows patients to note preferences regarding goals of care, as well as to nominate a healthcare power of attorney, or surrogate decision-maker, should they become incapacitated. Examples of medical orders that address life-sustaining care and may be part of an advance directive include ascertaining wishes about do-not-resuscitate (DNR) status; intubation and mechanical ventilation status; artificial hydration and nutrition status; use of antibiotics; desire for hospitalizations; and other desired medical interventions (i.e., New York State Department of Health [NYSDH], 2010; North Carolina Department of Health and Human Services, 2007).

While it is difficult to accurately predict preferences regarding future care (Sudore & Fried, 2010), engaging in this process early and then periodically allows for the exploration of goals of care in the context of individual values. Additionally, certain advance directives, such as the document used within the Veterans Health Administration, allow individuals to specify how strictly they would like their documented preferences followed. This has the benefit of allowing for adaptability in the context of changing or unforeseen circumstances, and the majority of

veterans may prefer this option (Mayer et al., 2017). Some jurisdictions also allow individuals to create medical orders regarding mental health care (i.e., Lenagh-Glue et al., 2020), reflecting the flexibility that individuals may have when documenting their preferences regarding future care. Given findings that suggest that individuals do not approach preparation for future care in a necessarily linear or organized fashion (Sörensen & Pinguart, 2000), this flexibility is critically important when engaging in any type of advance care planning.

As demonstrated in Study One, the use of health literacy screeners in primary care can help identify older adults with low functional health literacy. Early identification of these individuals may allow them to receive education and guidance from healthcare providers, including psychologists, regarding end-of-life planning, particularly as individuals with low health literacy have been shown to prefer more aggressive treatment without fully understanding the ramifications of these choices (Vollandes et al., 2008). In addition, individuals with low health literacy may prefer to access health information from unreliable sources such as television or social media rather than healthcare professionals or respected medical websites (Chen et al., 2018). This may be of particular importance when considering knowledge regarding life-sustaining treatments, as such procedures are often portrayed inaccurately in popular media. For example, individuals who regularly watch fictional medical shows demonstrate a poorer understanding of cardiopulmonary resuscitation (CPR) compared to those who do not (Colwill et al., 2018), and understanding of the risks and outcomes of CPR is low within the general U.S. population (Alexander et al., 2019). However, using an accurate video representation of CPR to educate older adults with advanced illness resulted in decreased chances of these patients desiring CPR (Kappell Brown et al., 2018). This again highlights the need for identification of patients with low health literacy, as early intervention may allow these individuals to make an

informed choice regarding end-of-life care or life-sustaining treatment. Such interventions with individuals with low health literacy may also have the added benefit of increasing satisfaction with healthcare (Örsal et al., 2019). Potential interventions include the use of strategies such as asking patients to repeat information in their own words, as well as providing written or visual aids (Noordman et al., 2019).

In addition to health literacy, an important factor to consider when discussing advance care planning is an individual's exposure to death. Findings within this area are mixed, as medical students who experience significant exposure to death have been shown to both maintain high levels of death anxiety (Wolf et al., 2020) and demonstrate increased comfort with death and the end-of-life process (Anderson et al., 2011). Similarly, the high death exposure that is typically experienced by physicians in certain healthcare fields has been shown to result in both positive (Granek et al., 2015) and negative (McFarland et al., 2017) consequences, demonstrating the importance of individual variability in responses to death exposure. Avoidance has been proposed as a potential moderating factor (Linley & Joseph, 2005) to explain the wide variety of ways in which individuals react to experiences with death, as avoidance may reinforce the idea of death as a negative outcome.

As with health literacy, it is easy to overestimate knowledge and/or comfort regarding death and the dying process (Hayes et al., 2020). All patients may benefit from monitoring and potential intervention, as death anxiety may prevent vulnerable individuals from engaging in advance care planning (Luth, 2016). Conversely, those who have completed an advance directive may have a great acceptance of death (Lynn et al., 2016). A wide variety of interventions have been shown to reduce death anxiety in older adults, including meaning-making (Rodin, 2017) and laughter therapy (Kuru Alici et al., 2018), and reducing this anxiety may have important

implications for greater engagement with end-of-life planning. Finally, there may be a strong family component to comfort with death, as children, parents, and grandparents have been shown to demonstrate similar levels of death anxiety (Freytag & Rauscher, 2017). These findings emphasize the importance of considering family systems and communication when engaging in advance care planning discussions (Schmid et al., 2010). In addition, individuals with high death anxiety may be less likely to discuss end-of-life care with family members (Brown et al., 2014), which has negative implications if a family member is called upon to act as a surrogate decision-maker.

Study Two Hypotheses

Given the individual impact that health literacy and death exposure may have on advance care planning and choices, the aim of Study Two was to examine the main and interaction effects of these constructs on end-of-life care choices in a community sample. It is important to measure attitudes towards advance care planning in this population, as it is recommended that adults begin discussing their values and preferences regarding end-of-life care as soon as possible (Block et al., 2020). Although it is difficult to make predictions regarding future care (Sudore & Fried, 2010), it is potentially even more difficult and costly for patients and their families to make these choices following a medical crisis or incapacitation (Curtis et al., 2020). Therefore, it is important to understand the attitudes of community-dwelling adults, as this is an important population to target when engaging in advance care planning.

While previous research (i.e., Volandes et al., 2008) has demonstrated that individuals with low health literacy are likely to prefer more aggressive end-of-life treatment, this effect may be dependent on death exposure, as individuals with high death exposure may prefer less aggressive end-of-life treatment options due to more familiarity with the dying process.

However, given the variability in how individuals respond to death exposure, this hypothesized interaction was largely exploratory. It was hypothesized that the following model (see Figure 2) would be an acceptable fit for the data ($X^2 p > .05$; RMSEA [root mean square error of approximation] $< .05$).

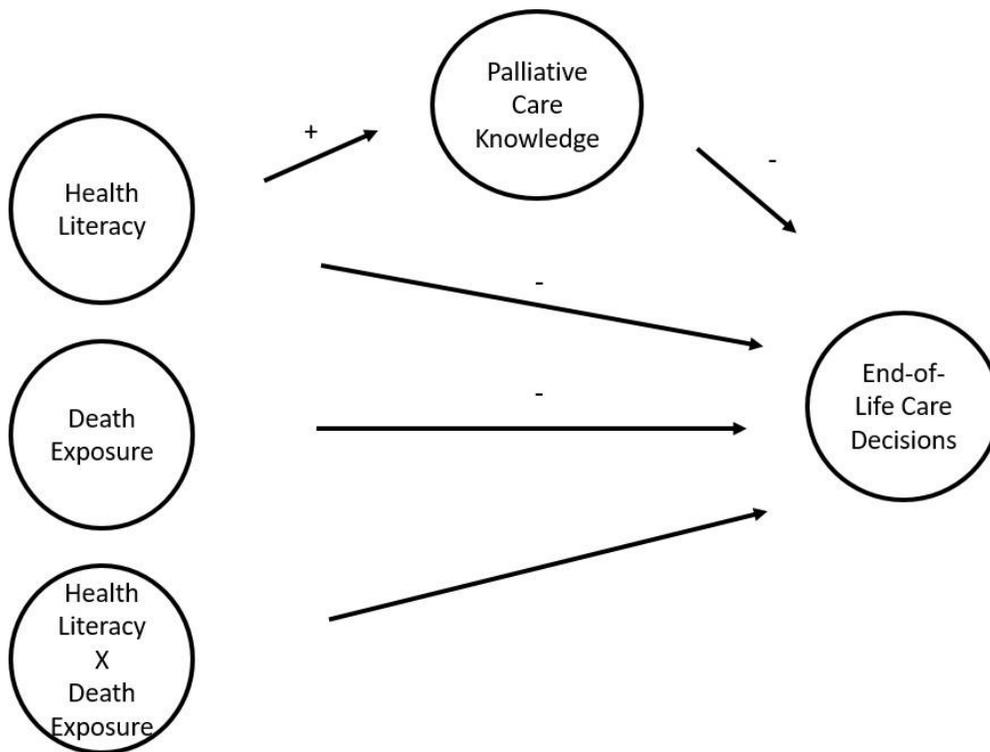


Figure 2. Initially Proposed Study Two Path Model.

An interaction was expected between health literacy and death exposure, as it was predicted that participants with low health literacy and high death exposure would prefer fewer interventions at the end of life. It was hypothesized that participants with low death exposure and low health literacy would prefer more aggressive end-of-life care options. This may include a greater likelihood to endorse life-sustaining practices such as CPR and intubation when asked about current end-of-life care preferences. In contrast, it was hypothesized that those with high

death exposure and low health literacy would prefer less aggressive end-of-life care, as they were expected to have greater experience with the nature of end-of-life care. Finally, it was hypothesized that participants with high health literacy and high death exposure would prefer less aggressive end-of-life care options, while participants with high health literacy and low death exposure were expected to be more variable in end-of-life care preferences.

Within the proposed model, participants' knowledge of palliative care was predicted to mediate the relationship between health literacy and end-of-life care decisions, and high health literacy was hypothesized to be predictive of high palliative care knowledge, which in turn was expected to result in preference for fewer interventions at the end of life.

Study Two Methods

Study Two Participants and Procedure

Ethical approval for this study was granted by The University of Alabama Institutional Review Board for research involving human subjects (Protocol Approval Number: 19-03-2125). Participants provided online informed consent to participate before beginning the study, and all data collection took place in June of 2019 prior to the COVID-19 pandemic.

Participants in this study were recruited through Amazon's Mechanical Turk (MTurk) crowdsourcing platform, as this method of recruitment allows for the sampling of diverse participants from various areas of the country. All participants were at least 18 years of age and citizens of the United States. While MTurk has previously been criticized for having lower levels of diversity than the general U.S. population, participant attention when completing research studies is significantly higher compared to other online platforms (Beymer et al., 2017). In

addition, more diverse participants can be reached through online recruitment when compared to research conducted with college undergraduate samples (Casler et al., 2013).

A minimum of 200 participants was desired based on the proposed model (see Figure 2 in section Study Two Hypotheses), as this satisfies the requirement of 20 participants per variable (Kline, 1998) and a minimum of 200 participants per model (MacCallum et al., 1996). While 200 participants would yield sufficient power, oversampling was necessary given the likelihood of participant attrition and/or random responding. Ultimately, 380 participants were recruited for the study. Sixty-eight participants were excluded from data analyses based on failing embedded attention check questions, resulting in a final sample of 312. As data for participants who failed attention checks were not collected, demographic comparisons between participants who successfully completed the study versus those who did not are not available.

Participants were paid \$0.50 for completing all questionnaires. Successful completion of all attention check questions was required for compensation, which is consistent with MTurk policies and was outlined in the consent form. As data collection took place entirely online, participants viewed the consent form prior to beginning the study and provided consent by acknowledging that they had read and understood study policies and procedures. No personally identifying information was collected, and payment was administered via MTurk identification number. While researchers may view MTurk identification numbers, personally identifying information associated with these accounts is held securely by Amazon and cannot be accessed by researchers. Participants accessed questionnaires through the MTurk platform, and all measures were administered via Qualtrics in a randomized order.

Measures

Demographic data, including age, race, gender, marital status, income, current health conditions, and level of education, was collected from all participants.

Health literacy. Similar to Study One, the Newest Vital Sign (NVS; Weiss et al., 2005) was again used to measure functional health literacy. As discussed in Study One, the NVS provides information about a patient's ability to use and apply health information in the context of objective health literacy, and it may have lower face validity than other similar measures (VanGeest et al., 2010). The NVS was included to provide information about participants' functional health literacy abilities as a more objective measure when compared to subjective indicators of this construct. While the NVS is designed for in-person administration, prior research has successfully utilized this measure in an online setting (Albright & Allen, 2018; Chen et al, 2018), and recent findings suggest that computer administration is valid (Mansfield et al., 2018; Weiss, 2018).

Advance directive/medical orders. All participants were asked if they possessed an advance directive, and the following definition (Illinois Department of Public Health, 2018) of this term was provided:

You have the right to make decisions about the health care you get now and in the future.

An advance directive is a written statement you prepare that expresses how you want medical decisions made in the future should you not be able to make them yourself.

When physicians assess what medical interventions are desired by patients, it is typical to use a highly technical and legally binding document (i.e., the New York Medical Orders for Life-Sustaining Treatment form [MOLST]; NYSDH, 2010]). Due to the formal and legal nature of such documents, participants were presented with questions adapted from the MOLST rather

than being asked to complete the actual form. These questions assessed for desire for CPR; desire for full scope of treatment, limited intervention, or comfort care only; administration of antibiotics; and administration of artificial hydration and nutrition. To create a variable reflecting aggressiveness of end-of-life care preferences, the number of interventions endorsed was summed. Possible scores range from 6 to 15, with higher scores reflecting a desire for more aggressive care.

Life-sustaining treatment questions were modified for the purposes of the current study, as terminology may be challenging or confusing for individuals who are not experienced with complex medical terms or language (Mueller et al., 2010). Participants were provided with definitions of medical concepts to facilitate understanding, which may be particularly necessary for individuals with low health literacy. These definitions were taken from the California Advance Care Directive (CACD; Sudore et al., 2007), a legal document that is written to be more accessible for those with low health literacy. The CACD utilizes graphical images and definitions to assist individuals with low health literacy in preparing an advance directive, and this document is written at an approximately fifth grade reading level. However, the CACD is focused on appointing a medical decision-maker or durable healthcare power of attorney, and the understanding of their role in the end-of-life process is emphasized. Specific items include assessing the desire for autopsy or organ donation, and use of this form would not provide the same information as would be obtained from a more comprehensive life-sustaining orders form such as the MOLST.

Death exposure. Death exposure was measured using the Death Exposure (DE) scale (Eichorst, 2017). While this is an unpublished measure, it was chosen due to a lack of a standardized or validated measure within the existing literature. The original DE scale consisted

of five questions that assess how much death an individual has been exposed to in the course of their lifetime. This scale was specifically created for use with Certified Nursing Assistants, and two questions specifically referred to this job title and deaths experienced in this course of this occupation. This measure was modified to assess more general death exposure for participants in the proposed study, and only the first three general questions were included. These three questions were answered on a 10-point Likert scale that ranged from “not at all/almost none” to “very, very much,” with possible scores ranging from 3-to-30 and higher scores being indicative of greater death exposure. Internal consistency for the full scale has been demonstrated to be acceptable ($\alpha = 0.76$) when used in a relatively small sample of participants ($n = 110$). As the current study proposes to use a larger sample of individuals, performance of the DE scale may be evaluated for potential future use.

Palliative care knowledge. The Palliative Care Knowledge Scale (PaCKS; Kozlov, McDarby et al., 2018) was used to assess knowledge of palliative care. The PaCKS consists of 13 true/false questions regarding palliative care factual knowledge. Notably, the most recent publication of the PaCKS includes a “don’t know” option, which allows participants to indicate that they truly have a lack of knowledge, as opposed to a forced random response resulting in a 50% chance of guessing the correct answer. An answer of “don’t know” is considered to be incorrect when calculating the total score. The PaCKS has been administered to community-dwelling participants via MTurk, and higher scores indicate a greater knowledge of palliative care. This construct is particularly important to measure, as racial disparities exist within this domain; for example, African Americans may have lower overall knowledge of palliative services and advance care planning than NHW individuals (Noh et al., 2018).

Study Two Data Analysis

Path analysis, a form of structural equation modeling, compares a fully saturated statistical model that estimates all possible interrelations among a set of factors to a specified model with a reduced number of parameter estimates delineated according to hypothesized pathways through which the factors impact each other (Schumacker & Lomax, 2016). If the specified model approximates (i.e., does not significantly deviate from) the variance–covariance structure of the fully saturated model, it is considered a parsimonious and scientifically meaningful representation of the relations among variables. Path analysis is well-suited to working with correlational data, and concurrent relationships among observed variables may be determined (South & Jarnecke, 2017). For the present study, path analysis was conducted using LISREL 9.30 (Jöreskog & Sörbom, 2017).

Study Two Results

Of the 312 participants who successfully completed all questionnaires, the majority were female (58.5%) and NHW (78.8%), and 85.3% reported at least some college. Ages ranged from 19 to 83 ($M = 37.23$, $SD = 12.54$), although 95.5% of participants were under the age of 65. Full demographic information is summarized in Table 5. Correlations between the main variables of interest are summarized in Table 8.

Table 5. Demographic Variables of Study Two Participants (n = 312).

Measure	
Age, <i>M(SD)</i>	37.23 (12.53)
Over Age 50, <i>n (%)</i>	52 (18.7)
Gender, <i>n (%)</i>	
Female	182 (58.3)
Race/ethnicity, <i>n (%)</i>	
African American	20 (6.4)
American Indian	2 (0.6)
Asian	19 (6.1)
Hispanic	21 (6.7)
Non-Hispanic White	246 (78.8)
Multiracial	4 (1.3)
Education, <i>n (%)</i>	
Some High School	1 (0.3)
High School Diploma	29 (9.3)
Trade or Technical School	16 (5.1)
Some College	87 (27.9)
College Diploma	118 (37.8)
Some Graduate School	19 (6.1)
Graduate or Professional Degree	42 (13.5)
Have Children, <i>n (%)</i>	
Children Under Age 18	95 (30.4)

Health Literacy

As measured by the NVS (Weiss et al., 2005), 79.2% (n = 247) of participants displayed adequate functional health literacy, while 11.8% (n = 37) scored within the possibly limited range and 9.0% (n = 28) scored within the highly limited range (see Table 6). This represents a contrast to Study One, as only 44.1% of adults from the Geriatrics Clinic sample scored within the adequate range. Also in contrast to Study One, there was a significant positive association between health literacy and age ($r = .15, p < .01$) as opposed to a negative correlation. As patients under 50 years of age are not seen in Geriatrics Clinic, health literacy scores were compared between individuals both under (n = 260; 83.3%) and over (n = 52; 16.7%) the age of 50 in the current MTurk sample. Interestingly, participants over the age of 50 were found to have

significantly higher health literacy scores ($M = 4.96$, $SD = 1.34$) compared to their younger counterparts ($M = 4.50$, $SD = 1.73$), $t(88.57) = 2.15$, $p < .05$. While functional health literacy has been shown to decline as individuals age, particularly in the context of changes in cognition (Geboers et al., 2018; Kobayashi et al., 2016), older adults who self-select into an online study may be more cognitively intact than the community-dwelling individuals assessed in Study One.

Table 6. Descriptives of Study Two Variables ($n = 312$).

Measure		Possible Range
Newest Vital Sign (NVS), $M(SD)$	4.58 (1.68)	0-6
NVS Categorization, n (%)		
Adequate Health Literacy	247 (79.2%)	
Possibly Limited Health Literacy	37 (11.8%)	
Highly Limited Health Literacy	28 (9.0%)	
Death Exposure, $M(SD)$	11.36 (5.71)	3-30
Palliative Care Knowledge (PaCKS), $M(SD)$	7.68 (4.08)	0-13
Possessed Advance Directive, $M(SD)$	56 (17.9%)	-
End-of-Life Interventions, $M(SD)$	11.72 (1.94)	6-15

Females ($M = 4.81$, $SD = 1.50$) had significantly higher functional health literacy than males ($M = 4.25$, $SD = 1.86$), $t(236.18) = 2.85$, $p < .01$, which is consistent with Study One findings. A one-way ANOVA found no significant main effect of race on functional health literacy ($F(4, 305) = 1.43$, $p > .05$), and Tukey HSD post-hoc analysis did not demonstrate significant differences between groups. Of note, while two participants identified as American Indian, there was no variance within their functional health literacy scores, and these individuals were excluded from this ANOVA, as tests of equality of means cannot be performed in the context of zero variance. Given the differences in health literacy scores found between NHW and African American patients in Study One, a follow-up analysis was conducted to examine differences between these two groups specifically. As in Study One, NHW participants ($M =$

4.62, SD = 1.70) had significantly higher functional health literacy than African American participants (M = 3.75, SD = 1.97), $t(264) = 2.16, p < .05$. A one-way Welch's ANOVA did not demonstrate a significant main effect of highest degree on functional health literacy, $F(5, 68.66) = 1.72, p > .05$, and post-hoc analysis using the Games-Howell test demonstrated no significant differences between groups.

Death Exposure

Death exposure was measured using the DE scale (Eichorst, 2017), and scores ranged from 3 to 30 (M = 11.36, SD = 5.71). Surprisingly, there was no correlation between death exposure and age ($r = .01, p > .05$). There were no significant differences in death exposure based on participant gender or race.

Palliative Care Knowledge and End-of-Life Care

Knowledge of palliative care was measured using the PaCKS (Kozlov, McDarby, et al., 2018), and scores (see Figure 3) represented the widest possible range of 0 to 13 (M = 7.68, SD = 4.08). There was a significant correlation between age and PaCKS score ($r = .12, p < .05$), as palliative care knowledge increased with age. Females scored significantly higher (M = 8.29, SD = 3.91) than males (M = 6.81, SD = 4.18), $t(309) = 3.18, p < .001$. There was no main effect of race on palliative care knowledge, and post-hoc analysis using Tukey HSD did not demonstrate significant differences between groups.

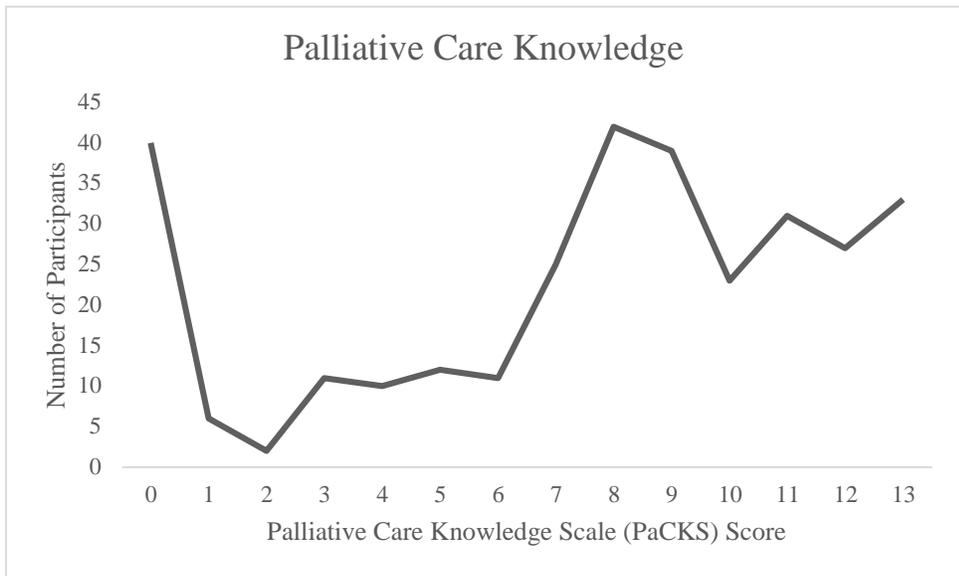


Figure 3. Study Two Participant Performance on the PaCKS.

Of the current sample, only 17.9% ($n = 56$) of participants reported having an advance directive. Participants with an advance directive did not differ significantly in terms of age, gender, education, race, death exposure, or palliative care knowledge from those who did not have an advance directive. However, a Chi-square test of independence demonstrated that participants who reported having children were more likely to have completed an advance directive, $\chi^2(1, 297) = 6.32, p < .05$. Additionally, individuals who had completed an advance directive had lower functional health literacy ($M = 3.45, SD = 2.29$) than those who did not ($M = 4.82, SD = 1.39$), $t(64.78) = -4.30, p < .001$. It is unclear if the advance directives of participants in the current sample contain life-sustaining orders, simply nominate a healthcare power of attorney, or both. This is an important distinction, as individuals with low health literacy are more likely to nominate a surrogate decision-maker rather than making complex medical decisions related to goals of care when creating an advance directive (Sudore et al., 2007).

Preference for end-of-life care was assessed through summing the number of interventions (i.e., CPR) that participants would currently desire at the end of life. Scores ranged from 6 to 15 ($M = 11.72$, $SD = 1.94$), with higher scores representing a preference for more aggressive care. Please see Table 7 for further information regarding desired interventions at the end of life. There was a negative correlation ($r = -.17$, $p < .01$) between age and aggressiveness of care, indicating that older participants were more likely to desire fewer interventions. A regression demonstrated that age ($\beta = -.17$, $p < .01$) was a significant predictor of end-of-life care choices, $F(1, 310) = 9.06$, $p < .01$, although this accounted for a relatively small amount of explained variance ($R^2 = .03$) of aggressiveness of desired care.

Table 7. Desire for end-of-life interventions by age group (n = 312).

Intervention	Under 50, % (n)	Over 50, % (n)
1. Cardiopulmonary Resuscitation (CPR)	80.0% (208)	63.5% (33)
2. Intubation	23.8% (62)	13.5% (7)
3. Trial Intubation	60.8% (158)	50.0% (26)
4. IV Fluids	83.8% (218)	76.9% (40)
5. Long-Term Feeding Tube	13.1% (34)	3.8% (2)
6. Trial Feeding Tube	69.6% (181)	61.5% (32)
7. Hospitalize	68.1% (177)	44.2% (23)
8. Use Antibiotics	60.8% (158)	63.5% (33)
9. Limited Antibiotic Use	32.3% (84)	30.8% (16)

There were no differences between end-of-life care preferences in terms of gender, race, education, number of serious health conditions, or having children. However, of the 150 participants who stated that they had children, those who reported that their children were under the age of 18 preferred more aggressive care ($M = 11.96$, $SD = 1.95$) compared to those whose children were older ($M = 11.09$, $SD = 2.27$), $t(148) = 2.47$, $p < .05$). Individuals who did not have an advance directive were more likely to prefer more aggressive care ($M = 11.81$, $SD = 1.90$) compared to those with an advance directive ($M = 11.18$, $SD = 2.04$), $t(295) = 2.22$, $p <$

.05. This is consistent with medical practice, as responders are required to default to the highest level of care in emergency situations in the absence of legally-binding documentation (Pearse et al., 2019).

Path Analysis

Table 8 displays the matrix of zero-order Pearson coefficients between functional health literacy, death exposure, palliative care knowledge, and aggressiveness of end-of-life care.

Table 8. Bivariate Correlations of Study Two Variables (n = 312).

Variable	1	2	3	4
1. Health Literacy	1.000			
2. EOL Care	.042	1.000		
3. Death Exposure	-.324***	-.072	1.000	
4. PaCKS	.100*	-.062	-.017	1.000

*** $p < .001$, * $p < .05$

As expected, there was a significant positive association between health literacy and palliative care knowledge; however, this correlation was relatively weak ($r = .10$, $p < .05$). There was a significant negative association between health literacy and death exposure ($r = -.32$, $p < .001$), indicating that individuals with higher health literacy experienced fewer deaths in their lives. Expected significant ($p < .05$) correlations were not observed between aggressiveness of end-of-life care and health literacy or death exposure.

A path model predicting aggressiveness of end-of-life care with separate paths from health literacy and death exposure, as well as an interaction between the two and a mediation path from health literacy via palliative care knowledge, was an acceptable fit to the data, $\chi^2(2, 312) = 0.11$, $p > .05$, RMSEA $< .001$. However, none of the individual paths within the model achieved statistical significance. Please see Table 9 for individual coefficients and goodness of fit statistics and Figure 4 for a graphical representation of the model.

Table 9. Equation Parameters and Model Fit Statistics for the Study Two Model (n = 312).

<i>Paths</i>	Standardized Path Coefficient	Unstandardized Path Coefficient	Standard Error	<i>t</i>
1. Health Literacy → PaCKS	0.10	0.10	0.06	1.78
2. PaCKS → EOL Care	- 0.07	- 0.07	0.06	- 1.16
3. Health Literacy → EOL Care	- 0.07	- 0.07	0.14	- 0.51
4. Death Exposure → EOL Care	- 0.16	- 0.16	0.14	-1.19
5. Health Literacy × Death Exposure → EOL Care	0.12	0.12	0.15	0.80
6. Health Literacy → EOL Care (Indirect via PaCKS)	- 0.01	- 0.01	0.01	-0.96
<i>Model Fit</i>				
χ^2	0.11			
df	2			
<i>p</i>	.945			
RMSEA	< .001			
GFI	.999			

Please note that no paths achieved statistical significance.

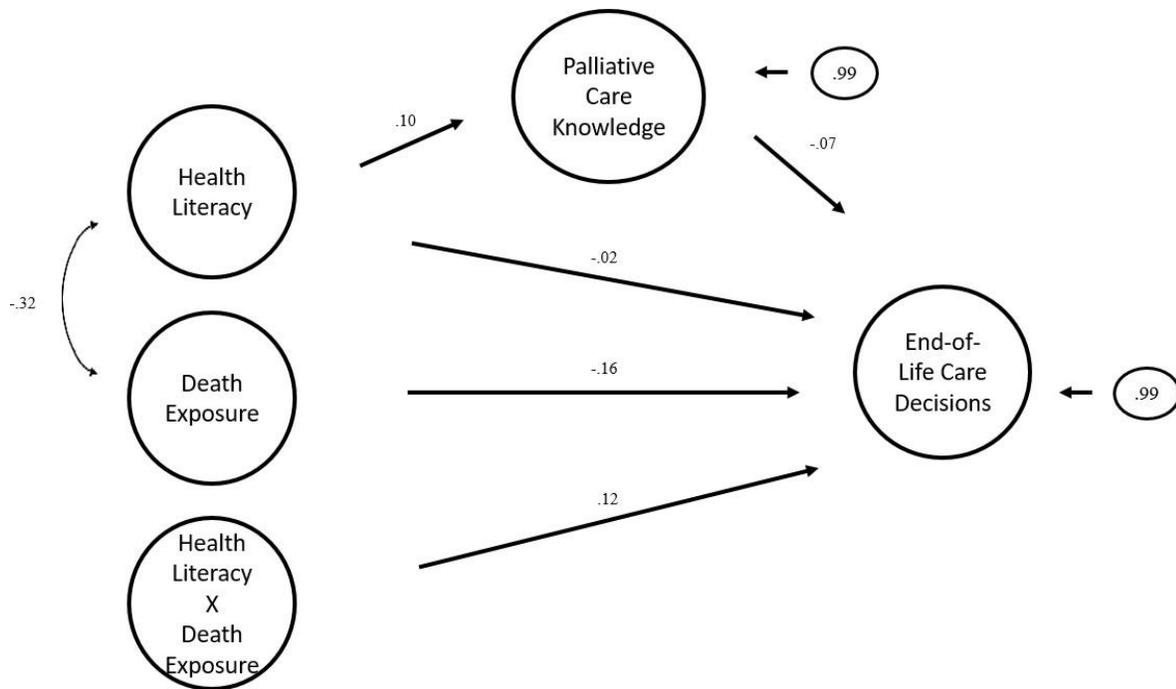


Figure 4. Proposed Path Model for Study Two.

Overall, the predictor variables accounted for 2.17% of the total variance of ($R^2 = .0217$), indicating that the observed variables did not sufficiently account for variance. As each equation accounted for approximately 1%, this resulted in high error variance ($1.00 - .01 = .99$). While the model was an acceptable fit for the data, given the low R^2 , it is likely that multiple predictor variables remain unaccounted for (Schumacker & Lomax, 2016). Given this, a forward regression was conducted to determine if palliative care knowledge, functional health literacy, death exposure, or an interaction of the latter two variables were predictive of aggressiveness of end-of-life care choices. None of these variables met statistical significance thresholds ($p < .05$), and therefore no variables were entered into the regression model. Finally, a one-way ANOVA was conducted to determine if death exposure moderated the relationship between health literacy and end-of-life care choices, and no main or interaction effects were found.

While the initially proposed model did not account for sufficient variability in aggressiveness of end-of-life care choices, individuals with children and individuals with no advance directive were significantly more likely to prefer more aggressive care. Therefore, the initially proposed model was tested in both of these groups. Unfortunately, while the model was again an acceptable fit for the data ($X^2 p > .05$, RMSEA $< .10$) in both samples, no paths were statistically significant. This remained the case as age was entered into the model as a predictor variable. As an example, Table 10 displays individual coefficients and goodness of fit statistics for the initially proposed model with participants who had children.

Table 10. Equation Parameters and Model Fit Statistics for Individuals with Children (n = 150).

<i>Paths</i>	Standardized Path Coefficient	Unstandardized Path Coefficient	Standard Error	<i>t</i>
1. Health Literacy → PaCKS	0.10	0.10	0.08	1.21
2. PaCKS → EOL Care	- 0.06	- 0.06	0.08	- 0.75
3. Health Literacy → EOL Care	- 0.01	- 0.01	0.19	- 0.04
4. Death Exposure → EOL Care	- 0.17	- 0.17	0.17	- 1.01
5. Health Literacy × Death Exposure → EOL Care	- 0.01	- 0.01	0.19	- 0.05
6. Health Literacy → EOL Care (Indirect via PaCKS)	- 0.01	- 0.01	0.01	- 0.76
<i>Model Fit</i>				
X^2	1.17			
df	2			
<i>p</i>	.555			
RMSEA	< .001			
GFI	.997			

Please note that no paths achieved statistical significance.

Study Two Discussion

Hypotheses regarding the impact of health literacy and death exposure on aggressiveness of end-of-life care choices were not supported. While the data was an acceptable fit for the overall path model, none of the individual pathways was significant, and neither health literacy, death exposure, nor an interaction of the two factors was predictive of desired end-of-life care. Palliative care knowledge did not act as a mediator between health literacy and end-of-life care. Additionally, given the low variance explained by the predictor variables, it is likely that multiple variables remain unaccounted for (Schumacker & Lomax, 2016) and may be explored further in future research.

Surprisingly, health literacy was not significantly associated with aggressiveness of end-of-life care decisions, which is inconsistent with prior research (i.e., Volandes et al., 2008) suggesting that those with low health literacy are likely to prefer more interventions. However, the current sample was relatively young, and a significant portion of participants had children under the age of 18, which may have impacted desire for more aggressive care irrespective of health literacy. For example, individuals may be more willing to undergo invasive treatment if this is in accordance with their values as a parent. Additionally, younger individuals are more likely to survive interventions such as CPR (Segal et al., 2018), and those with high health literacy may still desire aggressive care based on accurate and informed appraisals of risks and benefits. In the current sample, age was negatively associated with aggressive care, suggesting that those who were older did in fact desire fewer interventions at the end of life.

In contrast to Study One, more participants in the current sample had adequate functional health literacy as measured by the NVS (79.2% versus 44.1%). This is likely due to younger average age, as well as the nature of participant recruitment. While patients seen in Geriatrics

Clinic have to be capable of providing informed consent consistent with UA IRB policy, it is more cognitively challenging to engage with the MTurk platform, and a self-selection effect is likely. In addition, while participants in Study One were asked not to use a calculator or mathematical aids, this was unable to be enforced in the context of online administration, and it is possible that this allowed more Study Two participants to score within the adequate range. However, standardized administration of the NVS now allows for the use of a calculator or pen and pencil, as previous research has demonstrated that the use of such devices does not significantly impact scores (Weiss, 2018). This is consistent with the concept of functional health literacy, as, while basic literacy and numeracy skills are certainly beneficial (Nutbeam, 2000; Nutbeam, 2008), knowing how to understand and interpret the NVS nutrition label is more indicative of the ability to use health information meaningfully.

Less than 20% of participants within the current sample indicated that they possessed an advance directive, which is consistent with overall low completion rates of this document in the general U.S. public (Wickersham et al., 2019). This has potentially negative consequences for public health given the high physical, emotional, and financial costs associated with receiving unwanted care at the end of life (Goldberg et al., 2019; Mack et al., 2010). Interventions that provide education and highlight the need to engage in advance care planning are crucial, and it is important that such interventions be accessible for individuals with low health literacy. While lack of time may be a serious barrier to engaging in advance care planning with medical professionals (Nelson-Brantley et al., 2020), recent research has shown that education and documentation can take place without additional provider burden. For example, older adults were directed to a website designed to be accessible for those with low health literacy that contained information about advance care planning, including videos and step-by-step guidelines for

creating an advance directive in accordance with goals and values (Sudore et al., 2017). These older adults were more likely to both have an advance directive in their medical record and engage in advance care planning with physicians at follow-up, indicating that such interventions may be highly effective.

While the intervention designed by Sudore and colleagues (2017) was able to successfully utilize a website that individuals with low health literacy could easily navigate, many older adults may not have the means or ability to access a computer. This may include residents of skilled nursing facilities, who are at risk to lack an advance directive (Kurella Tamura et al., 2017) and are medically vulnerable. Given current public health challenges related to COVID-19 that may limit interactions with residents of long-term care facilities, novel methods of advance care planning may need to be explored. Unfortunately, a study examining the aggressiveness of end-of-life care choices in long-term care residents found that short educational videos on this topic had no effect on subsequent treatment decisions (Mitchell et al., 2020).

The 56 individuals in the current sample who stated that they had an advance directive had significantly lower functional health literacy than those who had no advance directive. This was a surprising finding, as prior research (i.e., Nouri et al., 2019; Waite et al., 2013) has demonstrated that those with high health literacy are more likely to possess an advance directive. No information was collected regarding the content of participants' advance directives, and so it is again unclear if these documents nominate a durable power of attorney for healthcare and/or contain life-sustaining orders. However, individuals are far more likely to possess an advance directive simply naming a surrogate decision-maker as opposed to possessing an advance directive that both names a healthcare power of attorney and documents goals of care (Kurella

Tamura et al., 2017). The ability to name a healthcare power of attorney may be less dependent on health literacy than making decisions regarding life-sustaining orders, and this may be a more feasible option for individuals with low health literacy (Sudore et al., 2007). It is also unclear why individuals in the sample chose to create an advance directive, and multiple other factors, such as family or provider involvement, may contribute to this finding.

Palliative care knowledge in the current sample was relatively low, which is consistent with prior research (i.e., Kozlov, Cai, et al., 2018). This is a highly significant area of study, as early interventions that address low knowledge and are process-oriented and flexible may improve quality of life outcomes for families and patients (Dionne-Odom et al., 2018). Although health literacy and palliative care knowledge were positively correlated in the current study, this association was relatively weak, reinforcing that high health literacy does not necessarily imply adequate understanding of palliative care. It is recommended that physicians continuously assess for patient knowledge and understanding of information in a palliative context, particularly in individuals with low health literacy, as these patients may be less likely to ask questions (Noordman et al., 2019).

Surprisingly, there was no main effect of race on palliative care knowledge, despite prior evidence that African American individuals have less experience and knowledge regarding palliative care than NHW individuals (i.e., Huang et al., 2016). However, it should be noted that the current sample only contained 20 African American participants, and there may have been a self-selection effect given MTurk administration. A recent study of community-dwelling adults in which racial groups were more balanced demonstrated that African American individuals had lower knowledge of hospice than NHW individuals (Noh et al., 2018), and it is likely that the lack of diversity in the current sample contributed to a null finding.

Of note, participants in the current sample scored higher on the PaCKS than in the initial study conducted by Kozlov and colleagues (2018), despite administration taking place through MTurk in both instances. While participants were asked to use their own knowledge rather than looking up the answers to questions, it is not possible to ensure adherence to this methodological issue given online administration. However, this was also a limitation of the initial study, and it is unknown why this difference was found. While the original sample contained more older adults, age was positively correlated with PaCKS scores in the Study Two sample, and it is unlikely that age explains this discrepancy. To our knowledge, no other studies have utilized this measure at this time, and it is possible that further research with the PaCKS may provide clarification.

Study Two Limitations

As with any research, the current study had limitations. Possession of an advance directive was determined by participant self-report and could not be independently confirmed, and it is therefore possible that this was not accurately reported. However, reported completion rates were generally concordant with expectations given a U.S. community sample. While every effort was made to ensure understanding of complex medical terms by using validated definitions created for those with low health literacy (Sudore et al., 2007), it is possible that participants did not fully understand what end-of-life interventions entail. Additionally, participants were limited in terms of diversity, as the majority were under the age of 65 and NHW. Given well-known disparities in advance care planning between NHW and African American individuals (i.e., Jeong et al., 2015; Noh et al., 2018), it is difficult to draw conclusions regarding the effects of race/ethnicity from the current sample.

Finally, it must be noted that participants in this study were asked to make hypothetical decisions regarding care they believed they would want at the end of life. This is an inherently difficult exercise (Sudore & Fried, 2010) given the infinite possible scenarios and conditions in which the end of life can occur, and even people for whom death may be imminent can and do change their goals of care as circumstances evolve (Kappel Brown et al, 2018). However, this is reflective of real-world advance care planning, as individuals are making the same hypothetical decisions when creating legally-binding documentation, and beginning to consider these issues as early as possible is highly beneficial (Block et al., 2020). It is hoped that beginning conversations early allows patients and their families to explore values and potential contexts, as it is potentially even more difficult for a surrogate to make end-of-life care decisions with no knowledge of the patient's wishes. One large medical system, the Veterans Health Administration, allows veterans to express through their advance directive how closely they want their stated decisions to be followed should they become incapacitated (Mayer et al., 2017). This flexibility may increase comfort with care planning, and this approach may become increasingly common.

Study Two Conclusions

Given the limited medical resources that are available at this time due to the COVID-19 - pandemic, it is vitally important to ensure that patients are not receiving undesired care at the end of life. As an ethical complication, given the increase in patients who have been unable to engage in advance care planning in either a medical or familial setting, it is suggested that physicians may need to make decisions regarding the discontinuation of life-sustaining care for patients who are unable to do so (Curtis et al., 2020). Therefore, interventions are urgently needed to ensure

that individuals and families are able to prepare for a “good death” while they have the capacity and resources to do so.

In a palliative care context, the goal of providing patients with a “good death” may alleviate some of the distress that is typically associated with the loss of a patient (Hirooka et al., 2017), as this approach focuses on the individual goals and values of patients and their families. The general emphasis on quality of life in palliative care settings may contribute to fewer complications related to bereavement following the death of a patient (Wright et al., 2008). This may explain why some experienced palliative care providers display greater acceptance and comfort regarding the dying process, although it should be noted that working with individuals at the end of life is an inherently difficult process (Green et al., 2018).

An end-of-life option for certain individuals within the United States is physician-assisted death (PAD), which is currently a topic of ethical and political debate on both a national and international level. Study Three assessed attitudes towards PAD, which were considered likely to vary considerably. Despite the importance of this topic, to our knowledge, there have been no studies examining the impact that health literacy may have on attitudes towards PAD. However, a recent survey of members of the American Geriatrics Society found that providers cited low health literacy as a complication if a patient is requesting PAD (Rosenberg et al., 2020). Given the percentage of participants in Studies One and Two who had inadequate functional health literacy, it is important to consider how this may impact an individual’s attitudes or perceptions towards PAD. Medical aid in dying is becoming increasingly available in multiple jurisdictions around the world, and having the option to hasten the dying process may contribute to an individual’s perception of a “good death.”

STUDY THREE OVERVIEW

Death is an inevitable part of life, although mortality is a topic that many individuals feel uncomfortable discussing. The concept of a “good death” refers to the idea that patients are able to retain some degree of autonomy regarding the end of life, although this is highly dependent on personal preferences and cultural background (Kastbom et al., 2017). A good death may include factors such as controlling pain, increasing acceptance of death, and dying at home.

Unfortunately, the majority of older adults tend to experience extended death trajectories due to chronic health conditions (Pollock & Seymour, 2018). Up to 75% of U.S. older adults experience hospital visits in the last few months of life and ultimately pass away while hospitalized rather than at home, which is frequently difficult for patients and their families (Smith et al., 2012).

Death exposure may be particularly important to consider in this context, as seeing others experience a negative dying process may affect an individual’s concept of a good death and their preferences regarding future care (Kastbom et al., 2017).

Quality of life and a desire for autonomy are highly individualized, as what may be acceptable to one individual may be intolerable to another (Carpenter & Merz, 2020). Given the increasing availability of PAD on both a national and international level, having the option to hasten or control the dying process may contribute to a patient’s perception of a good death. As demonstrated in Study Two, individuals may be highly variable in their desire for aggressive versus comfort care at the end of life, and this may be due to various factors such as age or having children. Study Three explored factors that influence support or opposition of PAD,

including health literacy and death exposure. As demonstrated in Studies One and Two, these constructs are highly variable within the general population, and it is important to understand how these factors may influence attitudes regarding this controversial end-of-life care choice.

Selection of terminology for Study Three was highly important. While the term “death with dignity” is frequently utilized within U.S. PAD laws, it may be argued that this may be used to pressure individuals from stigmatized groups into choosing this option as a way to preserve dignity and minimize the burden to others. This may include individuals with a variety of physical and cognitive disabilities (Marrie et al., 2017), particularly if others make inaccurate judgments about their subjective quality of life (Coleman, 2010; Schwartz & Lutfiyya, 2009). Additionally, suicide may be viewed as more acceptable in older adults compared to their younger counterparts. For example, approximately one quarter of community-dwelling participants surveyed in the Netherlands stated that PAD was acceptable for older adults without serious medical conditions who are simply “tired of living” (Raijmakers et al., 2015). For Study Three, the term “medical assistance in dying” or “assisted dying” was used whenever possible in participant materials in an attempt to lessen the emotional impact of words such as “dignity” or “suicide.” This terminology is consistent with the American Psychological Association’s (2017) resolution on this topic.

While, to our knowledge, there have been no studies explicitly examining how health literacy impacts views of PAD, various studies have examined attitudes towards PAD in groups that can be assumed to have high functional health literacy. For example, palliative care physicians have been shown to generally oppose PAD (Belanger et al., 2019), while a more general group of healthcare professionals has been shown to generally support PAD (Braverman et al., 2017). Recent studies of community participants have found that general support for

medical aid in dying is relatively high, particularly for individuals who do not identify as religious (Periyakoil et al., 2016), and health literacy is expected to be more variable in these participants.

Most jurisdictions that allow PAD have multiple criteria that patients must meet to be eligible for medical aid in dying. Within the United States, PAD is currently available for residents of Colorado, Hawaii, Maine, Montana, New Jersey, Oregon, Vermont, Washington D.C., and Washington. These conditions require that individuals seeking PAD must have a terminal condition with less than six months to live, be at least 18 years of age, and have the ability to make autonomous medical decisions (Emanuel et al., 2016). Unfortunately, there may be disparities in access to PAD in U.S. jurisdictions in which it is legal, as the cost of the prescribed drugs may range from several hundred to several thousand dollars (Shankaran et al., 2017). As a further complication, the barbiturates typically prescribed for patients seeking PAD were frequently used in U.S. capital punishment cases, and subsequent decreased production of these medications in response to this has made the cost even more potentially prohibitive (Riley, 2017). Additionally, individuals frequently need to gain assent from two physicians (Carpenter & Merz, 2020), creating further inaccessibility for those without health insurance or limited financial means.

Patients seeking PAD must not be experiencing psychopathology that may interfere with their ability to make medical decisions (Carpenter & Merz, 2020). Mental health may be particularly important to assess in these cases; for example, individuals with terminal illnesses report a greater desire to end their own lives if they are experiencing clinically significant symptoms of depression (Chochinov et al., 1995). While conditions such as depression frequently respond well to treatment and may impact an individual's desire to seek PAD, it is

important to note that the presence of suicidal ideation does not necessarily preclude medical aid in dying (Henman, 2017). This may be true regardless of whether or not the suicidal ideation is long-standing, as patients may still meet all other criteria for PAD (i.e., imminent death due to terminal illness). Individuals with suicidal ideation may create legally-binding advance directives that include DNR orders, and there is an ethical debate regarding whether or not these orders should be followed if the patient requires resuscitation due to a suicide attempt (Brown et al., 2013). This may be particularly salient for patients who live in jurisdictions in which PAD is not legal (Craig & Dzen, 2018) and are in the end stages of illnesses for which patients typically seek PAD (i.e., cancer or amyotrophic lateral sclerosis).

Ethical and moral standards must also be considered within the medical community, as a strong cultural value of many physicians is the preservation of life. The Hippocratic Oath has been in existence for approximately 2500 years, and it is a highly ceremonial part of both induction and graduation ceremonies in medical training (Degnin, 1997). Many physicians internalize this concept to a great extent, and it may be difficult to view the idea of actively working to end a life as consistent with one's professional duties. This may also be a separate concept from legislation, as medical ethics codes do not necessarily follow legal statutes. For example, while assistance with suicide has been decriminalized in Germany, the Federal Medical Association explicitly prohibits this practice by members (Emanuel et al., 2016).

When discussing the ethics of PAD, it is important to note that there are no universal standards of "right" or "wrong," and attitudes may be highly influenced by cultural factors, including religiosity (Bulmer et al., 2017). Hendry and colleagues (2012) discuss the importance of religious mores and ideals in a comprehensive review; for example, they note that medical aid in dying is not accepted in traditionally Protestant areas of the world. This is a concept that may

be found in other religions, particularly in non-Western cultures. Judaism and Islam do not allow for the hastening of death, while some Protestant churches allow euthanasia (Romain & Sprung, 2014). Interestingly, of the major religions reviewed, only Greek Orthodoxy prohibited double effect treatment, or the prescription of potentially lethal doses of medication in an attempt to control pain in dying patients (Hendry et al., 2012). This emphasizes the importance that the social context may have when analyzing cultural values and perspectives. The majority religious group of an area has a major impact on the development of legislation, which may explain why some jurisdictions do not allow PAD. None of the U.S. states that currently allow medical aid in dying are part of the Southeastern United States, and this is likely due to the conservative religious and moral standards common within this region.

Despite the increasing availability, PAD remains a topic of great political and ethical debate. Both support and dissent may often be understood by examining the context in which legislation is proposed, enacted, or denied. While PAD is a controversial topic, having the ability to take control of one's death may promote human agency and allow individuals to retain some amount of autonomy (Carpenter & Merz, 2020). However, while medical aid in dying is not an option that most patients are willing or able to access, simply having the ability to make this choice and experience a "good death" may be comforting to patients and their families who are coping with terminal illness.

Study Three Hypotheses

While Study Three was largely exploratory in nature, religiosity was a variable of particular interest, as this has been shown to influence the perceived acceptability of PAD in individuals of varying health literacy, including physicians (Voorhees et al., 2014) and community members (Bulmer et al, 2017). When considering support for PAD as measured by

participants' opinions regarding legalization of this practice, it was hypothesized that the following path model (see Figure 5) would be an acceptable fit ($\chi^2 p > .05$; RMSEA $< .05$) for the data.

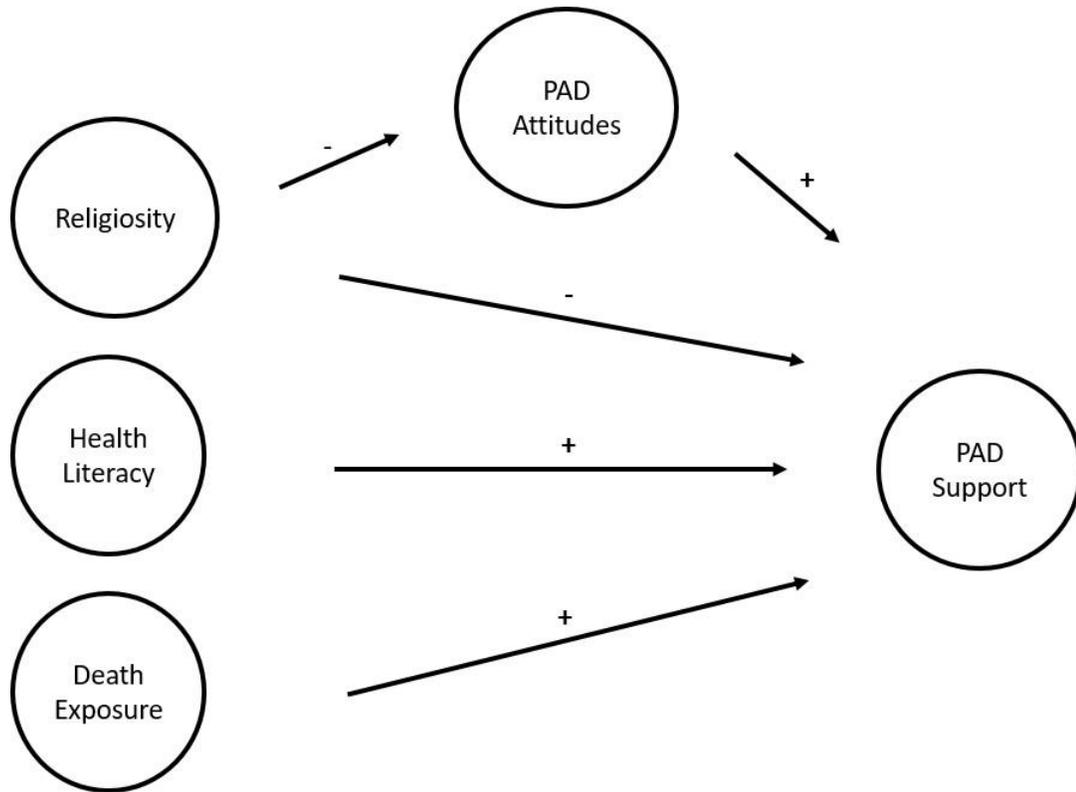


Figure 5. Proposed Path Model for Study Three.

It was hypothesized that attitudes towards PAD will mediate the relationship between religiosity and support for the legalization of PAD, as individuals who are highly religious are predicted to be less likely to support PAD. Participants with high health literacy are predicted to have greater support for PAD, although this hypothesis is largely exploratory. Participants with high death exposure are predicted to have greater support for PAD, as this has been demonstrated in prior studies involving community-dwelling participants (Claxton-Oldfield & Miller, 2015).

Study Three Methods

Study Three Participants and Procedure

After successful completion of Study Two on MTurk, all participants were given the option to complete Study Three for an additional \$0.50 (UA IRB Protocol Approval Number: 19-03-2125). It was clearly stated in the consent form and MTurk study description that participation in Study Three was not obligatory and would in no way affect payment for Study Two. Given the number of individuals who completed Study Two, this allowed for a maximum of 312 participants, and 200 participants were required for acceptable power (Kline, 1998; MacCallum et al., 1996) based on the proposed model (see Figure 5 in Study Three Hypotheses section).

If participants chose to complete Study Three, they were able to do so immediately following completion of Study Two. Measures were again presented to participants via Qualtrics, and surveys appeared in a randomized order. Successful completion of the study and payment were again dependent on participants accurately completing embedded attention check questions. As this was presented as a follow-up opportunity to Study Two, data collected through all other measures utilized in Study Two remained available. For the purposes of the present study, this included functional health literacy (NVS) and death exposure.

Study Three Additional Measures

Physician-assisted death attitudes and support. The Attitudes Toward Physician-Assisted Suicide scale (ATPAS; Claxton-Oldfield & Miller, 2015) was used to measure attitudes regarding PAD. The ATPAS contains 15 items, including questions regarding support for the potential legalization of PAD and its impact on quality of life. Participants responded to all items

on a five-point Likert scale that ranged from “strongly disagree” to “strongly agree.” For use in analyses, a total score with the potential range of 15 to 75 was computed, with higher scores indicating greater acceptance of PAD. Notably, this measure was initially used to compare PAD attitudes between a general community sample and hospice volunteers, a non-medical sample with high death exposure. As this measure was used with individuals without a high level of medical training, the language is relatively accessible, and complex medical terminology is not used. However, this measure does utilize the term “physician-assisted suicide” throughout, and this was changed to “medical assistance in dying” for the purposes of the current study. This language is consistent with APA (2017) terminology.

In addition to a quantitative measure of attitudes, a case vignette presenting a scenario involving PAD (Braverman et al., 2017) was used. This vignette describes a sample case of a patient who is eligible for PAD under current U.S. state laws in which PAD is legal (i.e., the patient is diagnosed with a terminal illness; is within the last six months of life; and has medical decision-making capacity). After reading a description of this fictional patient and his circumstances, participants were asked to indicate on a 7-point Likert scale if PAD in this hypothetical case is ethical and legally justifiable. They were then able to choose thematic items from a list to explain their support or opposition for PAD, including moral, ethical, and monetary reasons that may explain their reasoning. While these potential reasons were provided, participants also had the option to enter via free response any other justifications they may have.

Religiosity. As religiosity may influence preferences regarding end-of-life care and attitudes towards PAD, the Duke University Religion Index (DUREL; Koenig & Bussing, 2010) was utilized for Study Three. The DUREL is a brief five-item measure that assesses the domains of organizational religious activity, non-organizational religious activity, and intrinsic religiosity.

Participants responded to all questions on a five or six-point Likert scale in which they indicate how often they engage in particular religious activities and how applicable they find statements regarding religious beliefs. Responses were summed to create a total score for the current study, and possible scores range from 5-27, with higher scores representing higher religiosity.

Study Three Data Analysis

Path analysis was again used to compare a fully saturated statistical model to a specified model with a reduced number of parameter estimates delineated according to hypothesized pathways through which the factors impact each other (Schumacker & Lomax, 2016). As with Study Two, LISREL 9.30 (Jöreskog & Sörbom, 2017) was used for these analyses. Please refer to Figure 5 (in section Study Three Hypotheses) for a depiction of the proposed path model.

In addition to path analysis, multivariate analyses of variance (MANOVA) were conducted to explore individual differences between participants who base their support or opposition for PAD on specific themes. Using the ethical and legal themes provided by Braverman and colleagues (2017), participants were compared across groups for differences in levels of health literacy and death exposure. Unless otherwise stated, all other data were analyzed using bivariate Pearson correlations, Chi-square tests of independence, *t*-tests, or between-group ANOVAs.

Study Three Results

Of the 312 participants who successfully completed Study Two, 266 of these chose to also complete Study Three. Of these, one participant failed an embedded attention check and was removed from the study, resulting in a final total of 265 individuals. Of these participants, the majority remained female (62.6%) and NHW (79.6%), and ages ranged from 19 to 83 ($M =$

37.81, SD = 12.55). See Table 11 for a summary of demographic information. Females were significantly more likely than males to complete both studies, $X^2(1, 311) = 14.93, p < .001$.

There were no differences between these groups in terms of age or race/ethnicity.

Table 11. Study Three Demographic Variables (n = 266).

Measure	
Age, <i>M(SD)</i>	37.81 (12.55)
Over Age 50, <i>n (%)</i>	47 (17.7)
Gender, <i>n (%)</i>	
Female	166 (62.6)
Race/ethnicity, <i>n (%)</i>	
African American	15 (5.7)
American Indian	2 (0.8)
Asian	17 (6.4)
Hispanic	17 (6.4)
Non-Hispanic White	211 (79.6)
Multiracial	3 (1.1)
Education, <i>n (%)</i>	
Some High School	1 (0.4)
High School Diploma	21 (7.9)
Trade or Technical School	14 (5.3)
Some College	77 (29.1)
College Diploma	101 (38.1)
Some Graduate School	14 (5.3)
Graduate or Professional Degree	37 (14.0)
Have Children, <i>n (%)</i>	130 (49.1)
Children Under Age 18	81 (30.6)

As measured by the NVS, 82.6% (n = 219) of individuals in this sample had adequate functional health literacy, while 10.6% (n = 28) scored within the possibly limited range and 6.8% (n = 18) scored within the highly limited range. Participants who chose to complete both studies (M = 4.71, SD = 1.58) had significantly higher health literacy than those who opted to only complete Study Two (M = 3.78, SD = 1.99), $t(55.15) = -3.54, p < .01$. This is likely due to a self-selection effect, as well as the higher proportion of females in Study Three. Death exposure scores again ranged from 3 to 30 (M = 11.15, SD = 5.63) and did not differ significantly from

scores in Study Two. See Table 12 for further information regarding the main variables of interest in this sample.

Table 12. Descriptives of Study Three Variables (n = 266).

Measure	M(SD)	Possible Range
Health Literacy (NVS)	4.71 (1.58)	0-6
Death Exposure	11.15 (5.63)	3-30
Religiosity (DUREL)	13.42 (7.12)	5-27
PAD Attitudes (ATPAS)	52.92 (12.97)	15-75
PAD Support	5.48 (1.97)	1-7

Religiosity was measured using the DUREL (Koenig & Bussing, 2010), and the three subscales were summed to create a total score (M = 13.42, SD = 7.12). Interestingly, 24.5% (n = 65) of participants achieved the lowest score possible, indicating that they are not religious. There was a positive association between religiosity and age ($r = .21, p < .001$), as older participants were more likely to endorse religious beliefs and/or activities. Female participants (M = 14.63, SD = 7.16) scored significantly higher than male participants (M = 11.35, SD = 6.61), $t(216.94) = 3.78, p < .001$. An ANOVA demonstrated no main effect of race on DUREL scores, although this may be impacted by the relative lack of diversity within the current sample. Given prior research findings on this topic (Chatters et al., 2009), a follow-up *t*-test was conducted, and it was found that African American participants had significantly higher scores on the DUREL (M = 17.40, SD = 5.77) compared to NHW participants (M = 13.51, SD = 7.10), $t(17.18) = -2.48, p < .05$. This indicates that African American individuals in the current sample endorsed higher levels of religiosity than NHW individuals, although this finding should still be interpreted with caution given the relatively few number of African American participants.

Physician-Assisted Death

Attitudes towards PAD were assessed using the ATPAS (Claxton-Oldfield & Miller, 2015), and responses were summed to create a total score. Scores in the current sample ranged from 15 to 75 ($M = 52.92$, $SD = 12.97$), with higher scores indicating greater acceptance of PAD. There was no significant association between attitudes towards PAD and age ($r = -.02$, $p > .05$) or education ($r = -.05$, $p > .05$). Similarly, attitudes did not differ by gender ($t(256) = -.66$, $p > .05$) or by race/ethnicity ($F(5, 253) = .73$, $p > .05$). Tukey HSD post-hoc analysis did not demonstrate significant differences between racial/ethnic groups. As hypothesized, there was a significant association between ATPAS scores and functional health literacy, $r = .17$, $p < .01$, indicating that those with higher health literacy have more positive attitudes towards PAD.

In addition to the ATPAS, participants' beliefs and attitudes regarding PAD were assessed through use of a case vignette (Braverman et al., 2017) that described an elderly patient who ends his life through medical aid in dying provided by his physician. When asked whether this was ethically justified on a scale from 1 to 7, with 7 representing "completely", the majority of individuals agreed that it was ($M = 5.55$, $SD = 1.92$). Sixty-four percent ($n = 169$) of participants selected either a 6 or a 7, indicating a high level of agreement. In contrast, only 10.6% ($n = 28$) selected a 1 or a 2. Similarly, when asked if the presented scenario should be legal, 64.2% of participants selected either a 6 or a 7 ($M = 5.48$, $SD = 1.97$). This is consistent with the data obtained by Braverman and colleagues (2017), although it should be noted that their sample consisted of healthcare professionals rather than community-dwelling adults.

Participants were also asked to select reasons from a provided list for why they did or did not feel that PAD should be legal. Notably, 108 participants endorsed the idea that PAD creates a "slippery slope in that there would be too many possibilities for abuse if such actions were

legal.” The slippery slope argument was followed by religious beliefs (n = 45), suicide is always wrong (n = 38), good palliative care renders PAD unnecessary (n = 37), and physicians killing is always wrong (n = 27). A text box was provided to allow for free response, although the majority of participants did not utilize this. Four individuals reemphasized one of the provided themes, while one participant stated that PAD would be too hard on surviving family members.

When selecting reasons for why PAD should be legal, 184 participants stated that it relieves unnecessary suffering. This represents approximately 70% of the sample, indicating general support for PAD among respondents. This is consistent with prior research in both Canadian (Claxton-Oldfield & Miller, 2015) and American community-dwelling adults (Periyakoil et al., 2016). The second most selected reason was that people have the right to choose how to die (n = 167), followed by mercy (n = 143), death is a natural part of life (n = 108), physicians should not abandon patients (n = 75), and saving money for the healthcare system (n = 42). Again, the majority of participants did not provide a free response, but six individuals reiterated a provided theme. Interestingly, two individuals stated that PAD may prevent patients from becoming a burden to loved ones. Critics of the term “death with dignity” frequently cite this as a risk of PAD (i.e., Marrie et al., 2017), as fear of being a burden may cause individuals to seek PAD when they otherwise might not.

Using the ethical and legal themes from Braverman and colleagues (2017), MANOVAs were conducted to determine if participants in these groups differed in terms of functional health literacy or death exposure. There were no differences in terms of these constructs in individuals who had high ethical support for PAD versus low ethical support, $F(12, 514) = 1.18, p > .05$, Wilks' $\Lambda = .947$. Similarly, there were no differences between participants who had high versus low legal support for PAD, $F(12, 514) = 1.37, p > .05$, Wilks' $\Lambda = .939$.

Path Analysis

Table 13 displays the matrix of zero-order Pearson coefficients between functional health literacy, death exposure, religiosity, ATPAS scores, and support for the legalization of PAD. Of note, due to incomplete data, seven participants were excluded from the path model, resulting in a final total of 258 subjects. Significant correlations in the expected directions were found between religiosity, ATPAS scores, and PAD support, establishing a precedent for exploring the hypothesized mediating relationship. Expected significant correlations were not observed between health literacy or death exposure and support for PAD.

Table 13. Bivariate Correlations of Study Three Variables (n = 258).

Variable	1	2	3	4	5
1. Health Literacy	1.00				
2. Death Exposure	-.24***	1.00			
3. DUREL	-.10	.05	1.00		
4. ATPAS	.17***	-.03	-.53***	1.00	
5. PAD Support	.07	-.02	-.44***	.78***	1.00

*** $p < .001$

A path model predicting support for PAD with separate paths from religiosity, health literacy, and death exposure, as well as a mediation path from religiosity via ATPAS score, was an acceptable fit for the data, $\chi^2(2, 258) = 3.58, p > .05, RMSEA = .05$. While the RMSEA is equal to .05, it is still within the acceptable threshold, as it is below .10 (MacCallum et al., 1996). However, the direct pathways from health literacy, death exposure, and religiosity to PAD support were not significant. Please see Table 14 for individual coefficients and goodness of fit statistics and Figure 6 for a graphical representation of the model.

Table 14. Equation Parameters and Model Fit Statistics (n = 258).

<i>Paths</i>	Standardized Path Coefficient	Unstandardized Path Coefficient	Standard Error	<i>t</i>
1. DUREL → ATPAS	- 0.53	- 0.53	0.05	10.12***
2. ATPAS → PAD Support	0.78	0.78	0.04	17.37***
3. DUREL → PAD Support	- 0.04	- 0.04	0.05	- 0.83
4. Health Literacy → PAD Support	- 0.04	- 0.04	0.04	- 0.97
5. Death Exposure → PAD Support	- 0.002	- 0.001	0.04	- 0.04
Model Fit				
χ^2	3.58			
df	2			
<i>p</i>	.167			
RMSEA	.055			
GFI	.995			

****p* < .001

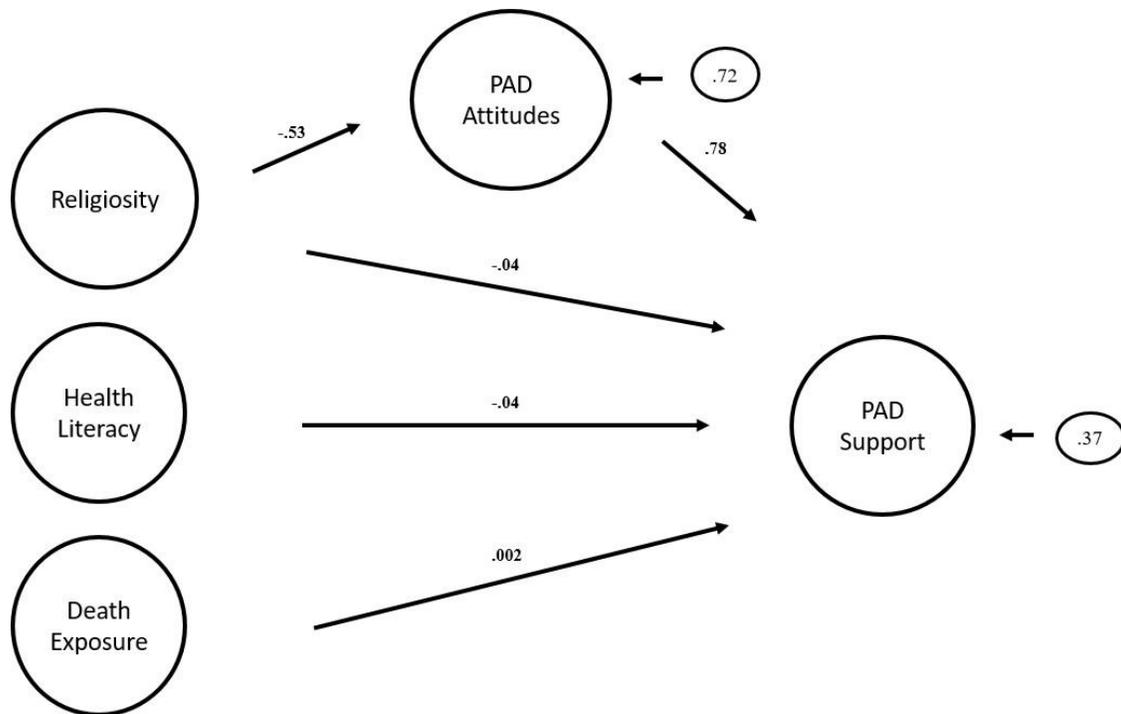


Figure 6. Path Diagram for the Proposed Study Three Model.

The direct path from religiosity to PAD support was not significant in the full hypothesized model ($t = -.83, p > .05$), and the total effect was therefore deconstructed into direct and indirect effects. This revealed that the indirect or mediation effect of religiosity via ATPAS scores significantly predicted PAD support ($t = -8.74, p < .05$), even though the direct effect did not. Because religiosity was fully mediated by ATPAS scores, its direct path to PAD support was dropped from the model. The adjusted model was an acceptable fit to the data, $X^2(3, 258) = 4.28, p > .05, RMSEA < .05$. Please see Table 15 for individual coefficients and goodness of fit statistics and Figure 7 for a graphical representation of the model.

Table 15. Equation Parameters and Model Fit Statistics for the Final Study Three Model (n = 258).

<i>Paths</i>	Standardized Path Coefficient	Unstandardized Path Coefficient	Standard Error	<i>t</i>
1. DUREL → ATPAS	- 0.53	- 0.53	0.05	10.12***
2. ATPAS → PAD Support	0.80	0.80	0.04	20.99***
3. DUREL → PAD Support (indirect)	- 0.43	- 0.43	0.05	- 9.11***
4. Health Literacy → PAD Support	- 0.04	- 0.04	0.04	- 0.95
5. Death Exposure → PAD Support	0.002	0.002	0.04	- 0.07
<i>Model Fit</i>				
χ^2	4.28			
df	3			
<i>p</i>	.233			
RMSEA	.041			
GFI	.993			

*** $p < .001$

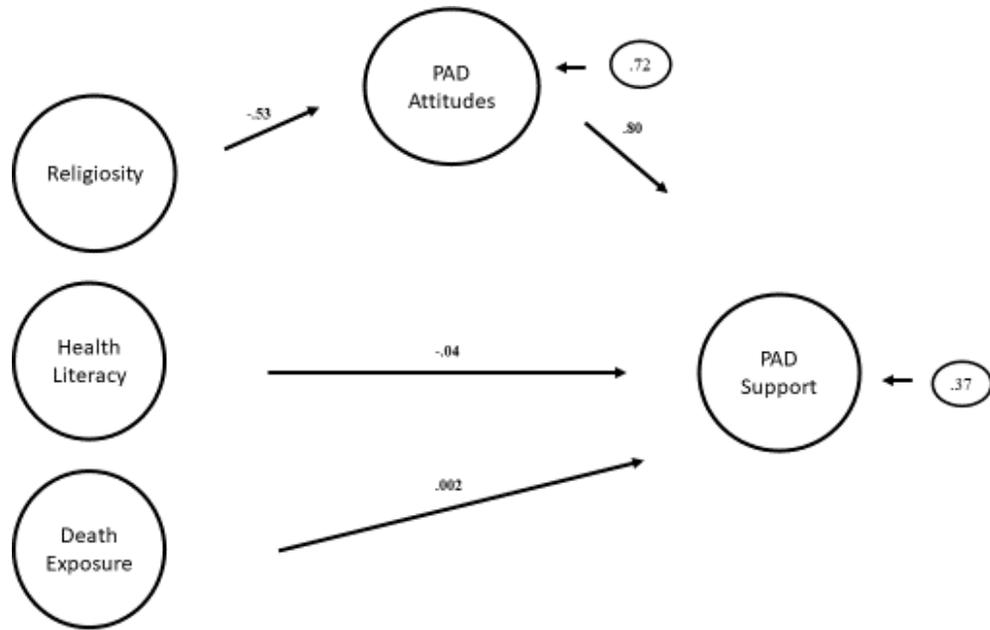


Figure 7. Final Path Diagram for the Study Three Model.

Higher religiosity significantly predicted more negative attitudes towards PAD as measured by the ATPAS, which in turn predicted less support for legalizing PAD. While there was no direct effect of either health literacy or death exposure on PAD support, removal of these variables from the path model resulted in unacceptable model fit ($\chi^2 p < .05$). This highlights the importance of these constructs' function in adjusting the parameters of other paths (Heinze & Dunkler, 2017), and they were retained in the model. Overall, the predictor variables accounted for roughly 63% of the total variance of PAD support ($R^2 = .631$), and the goodness of fit index (GFI) indicated that over 99% of the variance–covariance structure of the data was reproduced.

Study Three Discussion

It was hypothesized that individuals with high health literacy would report more favorable attitudes towards PAD, and this was supported by the data. While the majority of

participants in this study had adequate functional health literacy, this is not representative of the general U.S. population, and older adults are particularly at risk for low health literacy (Kutner et al., 2006; Wannasirikul et al., 2016). Therefore, patients with low health literacy who request information regarding PAD may benefit from extensive conversations with their healthcare provider to ensure adequate understanding and reasoning should they express further interest.

Hypotheses regarding the proposed path model were partially supported. While the initially proposed model was an acceptable fit for the data, the effect of religiosity on support for the legalization of PAD was fully mediated by ATPAS scores, or attitudes towards PAD. The direct pathway between religiosity and support for PAD was therefore removed from the model. Neither health literacy nor death exposure was found to have a significant direct effect on support for PAD, and these hypotheses were not supported. However, these variables were retained in the model, as their exclusion resulted in poor model fit.

While high religiosity was significantly associated with negative attitudes towards PAD, it is important to note that approximately 25% of participants in Study Three reported no religious behaviors or beliefs. A recent meta-analysis found that this is not uncommon for MTurk participants (Burnham et al., 2018), but it likely contributed to the high level of support for PAD within this sample and may not be representative of the general U.S. population in terms of religiosity. This is important to consider when working with patients who seek PAD, as it has been demonstrated that a sample of patients in Oregon who requested PAD were more likely to report no religious beliefs compared to terminally ill patients who did not request PAD (Smith et al., 2015). This also demonstrates the importance of terminology when discussing PAD, as the majority of major world religions do not find suicide acceptable based on moral and

ethical values (Khan & Mian, 2010). It is therefore important to avoid terms with a high emotional valence, such as “suicide,” when discussing medical aid in dying.

Participants in Study Three were generally in support of PAD, particularly in the context of respecting autonomy and minimizing suffering. However, the most common reason that participants selected as an argument against legalizing PAD was the idea of a “slippery slope,” meaning that legalizing PAD may lead to a greater relaxation of laws surrounding this practice, potentially placing vulnerable individuals such as older adults at risk. Even individuals who support PAD frequently cite this argument (Claxton-Oldfield & Miller, 2015), and this was also observed in the current study. This is important to be aware of, as 25% of community-dwelling participants in a Dutch survey reported the belief that older adults should be allowed access to PAD simply due to their age (Raijmakers et al., 2015). The Federal Medical Association of Germany’s code of ethics explicitly forbids members from providing medical aid in dying (Anneser et al., 2016; Emanuel et al., 2016) due to this risk, particularly given the cultural factors regarding atrocities involving euthanasia carried out by Nazi physicians during World War II (Oehmichen & Meissner, 2003).

Interestingly, 42 participants endorsed the idea that PAD should be legal due to the potential to save money for the healthcare system. While unwanted interventions at the end of life can certainly create financial burdens for patients and their families (Goldberg et al., 2019), care must be taken to ensure that individuals are not seeking PAD solely for financial reasons. Given this and the risk of a “slippery slope,” most jurisdictions that allow PAD strictly monitor and track cases in which individuals choose to end their own lives with medical assistance. For example, the Oregon Health Authority (2020a) tracks patients who receive lethal prescriptions and their physician by name, and subsequently publishes an annual de-identified report in which

statistics regarding PAD are made available to the public. Governmental oversight may be even more stringent for cases of euthanasia, which is currently not legal in any U.S. jurisdictions but is becoming increasingly common around the world.

As discussed in Study Two, advance directives are becoming increasingly flexible, allowing individuals to document individual preferences for future care (Mayer et al., 2017). In contrast, many jurisdictions will not honor requests for PAD made via advance directives, as only adults who retain medical decision-making capacity may request medical aid in dying. Despite this, documenting a preference for PAD in an advance directive may be highly beneficial for establishing goals and values, particularly if a capacity assessment is requested and the patient is found to have the capacity to request PAD (Carpenter & Merz, 2020). Several countries, including Belgium and the Netherlands, do allow individuals to receive euthanasia under certain conditions through preferences documented in an advance directive (De Vleminck et al., 2015). Taking into account the regular adjustments made to laws involving all forms of medical aid in dying, it may be important for U.S. adults to err on the side of caution and document strong wishes for PAD in their advance directives, despite the fact that this cannot be honored under current legislation.

Finally, while the proposed model was an acceptable fit for the data and study hypotheses were generally supported, it should be reiterated that PAD is a controversial topic, and legislation regarding PAD is subject to change. It is important to be aware of the attitudes and support for PAD held by community-dwelling individuals, as the societal and cultural context can have a strong impact on legalizing PAD. For example, Brittany Maynard, a California resident diagnosed with a terminal astrocytoma, moved to Oregon in 2014 in order to reside in a state with a death with dignity law (Maynard, 2014). Ms. Maynard was an active campaigner for

access to PAD, and she shared many details regarding her decisions prior to her death due to an overdose of a lethal medication legally prescribed by an Oregon physician. Her experience was widely covered by national media (Lauffer & Baker, 2020) and serves as an example of how societal context can influence legislation and attitudes regarding PAD.

Study Three Limitations

A limitation of the current study was the self-selecting nature of participants, which may be an internal validity issue for multiple studies that examine PAD. It was clearly stated in the consent form and MTurk study description that medical aid in dying was a focus of this study, and participants were able to choose whether or not they wanted to take part. Individuals who had a strong opposition to PAD or felt uncomfortable answering questions about this topic may have been more reluctant to participate, and this may have skewed attitudes towards PAD in a positive direction. In addition, while religiosity was measured using the DUREL, demographic information regarding religious affiliation was not collected, and it is therefore unknown if attitudes towards PAD would differ as a function of religious group.

As with Studies One and Two, the majority of participants were NHW females, reflecting a lack of diversity. This may be particularly impactful when considering influential factors such as religiosity, although prior research that is more representative of the general U.S. population has demonstrated that race and gender are not predictive of attitudes towards PAD (Periyakoil et al., 2016). However, NHW females have been shown to account for approximately half of all medically-assisted deaths in the U.S., despite this demographic being at relatively low risk for suicide (Canetto, 2019). This may be due to factors such as higher socioeconomic status and greater trust in the healthcare system when compared to women from racial/ethnic minority communities, which may be reflective of the differences between general support for PAD

versus actual utilization of this option at the end of life. Related to this, while the majority of individuals who access medical aid in dying in the United States are over the age of 65, economic factors remain important to consider (Shankaran et al., 2017). Even though U.S. adults in this age group have Medicare as their primary insurance, Medicare will not cover expenses related to PAD, as this is not a legally-recognized practice on a federal level. This requires that older adults who desire access to medical aid in dying possess a secondary health insurance policy, which serves to highlight economic disparities when utilizing this option.

Study Three Conclusions

Very few U.S. adults actually die via PAD; for example, in 2019, Oregon reported 290 prescriptions of lethal medication and 170 deaths due to this medication (Oregon Health Authority, 2020b). In contrast, the number of adults who die via PAD in Belgium and the Netherlands has been estimated to be almost 5% per year in a random sampling of death certificates taken in 2013 and 2015, respectively (Dierickx et al., 2020). This is consistent with the trend of PAD becoming increasingly common in these countries, and a similar pattern is being seen within U.S. jurisdictions (i.e., Oregon Health Authority, 2020b). Therefore, while utilization of medical aid in dying is still relatively low within the United States, it is important to understand how knowledge of beliefs and attitudes may provide insight into why patients do or do not choose this option at the end of life, particularly as this may influence future practices and legislation.

As the political landscape regarding PAD is constantly shifting, it is important to be aware of how community-dwelling adults view PAD. These individuals have a great deal of influence on legislation regarding medical aid in dying, as elected public officials are chosen by

their constituents. Therefore, the influence of factors such as religiosity are important to understand when considering the cultural and societal context of PAD support. While health literacy was not significantly associated with support for PAD in the current study, future research may focus on how palliative care knowledge impacts participants' attitudes and support for PAD.

GENERAL DISCUSSION

Taken together, the previous three studies demonstrate the importance of considering functional health literacy when engaging in advance care planning with older adults (Study One), while also considering its limitations (Studies Two and Three). Study One supported the need for establishing functional health literacy, as there may be discrepancies between objective measures and patients' subjective reports. This knowledge of the possible discrepancy between functional and subjective health literacy then allows healthcare providers to identify vulnerable individuals who may have difficulties deciding what care is desired at the end of life, and it is vitally important from an ethical standpoint (Halli-Tierney et al., 2018) to recognize individual differences regarding what makes a "good death." Advance care planning begins to establish preferences for future care, but it should be acknowledged that this is a difficult process given the uncertainty in making plans for future circumstances and the end of life. While determining preferences for future care is inherently difficult, this may be influenced by functional health literacy, as individuals with low health literacy may require additional interventions and education to ensure that they are making end-of-life care choices in accordance with their true values and preferences. This is particularly salient, as the prevalence of low health literacy is recognized as both a national and international concern (Paakkari & Okan, 2020) and may have a negative impact on overall public health.

In Study One, it was established that there was a difference between self-reported and objective, or functional, health literacy in community-dwelling older adults presenting in a

geriatric primary care clinic. While measures of subjective health literacy can provide important information regarding self-efficacy, it is important to note that there may be discrepancies between a patient's beliefs regarding their healthcare abilities and their true functional capabilities. As health literacy is an important predictor of factors such as medication compliance and treatment adherence (Miller, 2016), this is a vital construct to measure in healthcare settings. Similarly, functional health literacy may influence the ability to engage in shared decision-making with healthcare providers (Seo et al., 2016), and this is an important component of advance care planning.

As demonstrated in Study Two, the majority of participants surveyed did not have an advance directive, indicating that basic documentation regarding preparation for future care had not taken place. As participants in Study Two had relatively high functional health literacy, it is a public health concern that so few of these individuals had a documented advance directive. Contrary to expectations, functional health literacy and palliative care knowledge did not play a large role in the aggressiveness of future care choices (~2% of overall variance explained in the SEM model), illustrating the limitations of reliance on functional health literacy when engaging in goals of care discussions and designing interventions to increase advance care planning within the general population. Further variables of interest to explore may include factors such as how the meaning and purpose that individuals find within their own lives allows them to be more accepting of death (Wong, 2008), which may potentially influence fear of death and willingness to engage in advance care planning, regardless of functional health literacy.

The results of Study Three expanded upon the limitations found in Study Two regarding advance care planning by examining participants' attitudes towards physician-assisted death. While currently only an option in ten U.S. jurisdictions, the political landscape regarding medical

aid in dying is rapidly shifting. This is driven in large part by cultural and social contexts, and it is therefore important to understand the attitudes of community-dwelling adults towards PAD. In general, the majority of participants in Study Three reported support for the legalization of PAD, although a self-selecting effect may again have been present. Attitudes towards medical aid in dying acted as a mediating factor between religiosity and support for PAD, with individuals who reported strong religious beliefs being less likely to view PAD favorably. This is consistent with prior research (i.e., Smith et al., 2015), although it should be noted that approximately 25% of participants in Study Three did not identify as religious.

While participants in Study Three reported overall low levels of religiosity, this is consistent with typical MTurk samples (Burnham et al., 2018). When imminently confronted with one's own mortality, religious and/or spiritual beliefs may contribute to a sense of continued existence of self (Rosenblatt et al., 1989), and this may reduce fear of death and influence how individuals approach end-of-life decisions. Religiosity was measured using the DUREL, and it is important to note the difference between those who observe institutional rules regarding faith (i.e., "religious") versus those who relate to what they personally consider to be sacred on an individual level (i.e., "spiritual"; Nelson-Becker et al., 2015). It is an increasingly common trend within Western cultures for individuals to report a belief in the divine while not following organizational rules related to a particular religion (Malone & Dadswell, 2018), and this shift towards spirituality is particularly salient to consider in the context of the end of life. For example, while religious mores may influence attitudes towards PAD, as found in Study Three, spiritual individuals may be more variable in their beliefs depending on their personal values. When spirituality is a component of advance care planning, patients may experience less anxiety and avoidance regarding death due to the sense of overall life purpose or meaning

imparted by their personal beliefs (Ai & McCormick, 2010; Wong, 2008). Therefore, it is important to consider how spirituality, rather than only religiosity, may contribute to the interventions that individuals desire at the end of life, as this further allows for a patient's personal values and preferences to be acted upon. While the religiosity of participants in Study Three was assessed and was found to be fully mediated by attitudes towards PAD, spirituality was not measured, and this is a potential limitation and direction for future research.

Despite factors such as spirituality reducing death anxiety (Ai & McCormick, 2010), it should be noted that end-of-life planning in general is inherently difficult, and a lack of trained staff who are able to assist patients with this process may represent a further barrier to completion of documented preferences and advance directives. For example, social workers may be the profession that is most typically called upon to assist with the creation of these documents (Wang et al., 2017). Licensed social workers may be readily available in large medical centers, but this may not be the case for individuals who live in rural settings, and this may negatively impact the ability of these patients to create an advance directive. In these cases, initiation of advance care planning discussions may fall to primary care providers, who may lack comfort and training with this role (Nelson-Brantley et al., 2020). An additional common barrier cited by primary care providers is a lack of time to discuss advance care planning, and a feasible alternative may be training nursing staff to have more in-depth discussions with patients regarding care options (Hilgeman et al., 2018).

In Study Two, it was expected that an interaction between health literacy and death exposure would influence participants' desire for aggressiveness of end-of-life care. This hypothesis was not supported, and neither functional health literacy, death exposure, nor palliative care knowledge was predictive of the number of interventions desired at the end of life.

These constructs accounted for a very small portion of overall variance, and it is therefore assumed that multiple other predictor variables remain unaccounted for in the proposed model (Schumacker & Lomax, 2016). This may include factors such as spirituality, fear of death and subsequent attitudes towards death, self-efficacy, or a desire for autonomous versus shared decision-making, and further research in this area is required. Despite this, older adults were more likely to prefer fewer interventions, and participants with young children were likely to prefer more. It should be noted that the sample was relatively young ($M_{\text{Age}} = 37.23$, $SD = 12.54$), as only 4.5% of participants were over the age of 65. Given that younger adults are more likely to survive interventions such as CPR and are more likely to be caring for young children, it is not surprising that they may prefer more aggressive care (Segal et al., 2018), and it is possible that the age of the sample may explain why none of the expected constructs were predictive of aggressiveness of end-of-life care.

As demonstrated by Nutbeam's (2000) framework, overall health literacy is a broad construct that may be difficult to measure. Even when considering a single component, such as functional health literacy, this remains a complex factor that may be problematic to adequately capture. All three studies assessed functional health literacy using the NVS, a screener that is meant to provide information in a primary care context. The NVS was specifically designed to allow patients to work with health information in both numerical and written formats, and criterion validity during development was assessed by demonstrating significant positive correlations between NVS scores and other commonly-used measures of functional health literacy (Weiss et al., 2005), such as the Test of Objective Functional Health Literacy in Adults (TOFHLA; Parker et al., 1995) and REALM. While this suggests that these assessments are measuring the same construct, it should be acknowledged that this assumes that this construct is,

in fact, functional health literacy. However, the TOFHLA includes questions about basic health behaviors, including interpretation of instructions on a prescription medication bottle (Parker et al., 1995), and a patient being unable to do so accurately suggests that there is likely difficulty completing these tasks in a home environment.

As functional health literacy refers to the ways in which individuals are able to understand and apply health information (Nutbeam, 2000), skills-based questions included on measures may allow for further exploration and discussion of how the patient functions in terms of health behaviors. Screeners such as the NVS may be best utilized as a way to alert healthcare providers that there is a potential problem with a patient's functional health literacy without the significant time commitment of a longer measure (Weiss et al., 2005). This then allows the care team to have a discussion with the individual about their own understanding of their personal medical information and subsequent behaviors in more detail, which may result in the identification of areas in which the individual may be in need of assistance. For example, if a patient with diabetes has difficulty performing the ice cream nutrition label calculations required by the NVS, a discussion may ensue to ensure that they are able to adequately complete important behaviors such as medication and diet management. While existing measures are imperfect given the breadth of health literacy as a construct (Nutbeam, 2008), follow-up evaluation may then confirm that a patient's ability to find and use health information correctly is consistent with their performance on these measures.

When considering health behaviors and functional health literacy, it is important from both a public health and quality of life perspective that individuals understand the end-of-life care choices that they desire. While functional health literacy was not predictive of end-of-life care choices in Study Two, there was a significant positive correlation between functional health

literacy and palliative care knowledge. Of note, 12.8% (n = 40) of participants achieved a score of 0 on a measure of palliative care knowledge that contained thirteen questions, indicating very low understanding of this topic. While palliative care knowledge was positively associated with age in Study Two, it is likely that older adults who self-select into an online study are generally more cognitively healthy than the participants in Study One (Geriatrics Clinic). However, given the much higher functional health literacy of participants in Study Two, and the relationship between health literacy and palliative care knowledge, it is concerning that patients seen in Geriatrics Clinic may have low knowledge of what palliative care entails. Identification of low functional health literacy of patients in this clinic may help care providers assist patients with preparation for future care and documentation of preferences.

With this in mind, older adults generally express the paternalistic view that it is the responsibility of their physician or healthcare provider to begin advance care planning discussions (Sharp et al., 2013), increasing the risk that individuals who would otherwise be willing to engage in these conversations are not given the opportunity to express their preferences. Unfortunately, given the prevalence of chronic health conditions and comorbidities, many older adults die in hospitals or long-term care facilities rather than at home (Smith et al., 2012), even though home is frequently acknowledged as the preferred location for death (Kastbom et al., 2017). As hospitals or long-term care facilities are typically not the expressed preference for a good death, advance care planning discussions regarding aggressiveness of treatment should take place as early as possible to ensure that patients are receiving their desired care at the end of life and, if desired, have the opportunity to receive this care at home. Given the interdisciplinary nature of Geriatrics Clinic and regular screening of functional health literacy, patients in Study One are ideally situated to receive advance care planning assistance as needed.

Unfortunately, even when care preferences are clearly stated in an advance directive, a recent report found that almost 10% of patients in the United Kingdom with documented DNR orders still received CPR due to the difficulty of accessing these documents in emergency situations (Herbelet et al., 2020). Multiple jurisdictions have attempted to address this issue in various ways; for example, Oregon has created an electronic state database into which goals of care are entered, and providers may access this registry at any time. However, during a medical emergency, this often cannot be done due to the urgent nature of such crises (Schmidt et al., 2014). Other jurisdictions have created legally-recognized and easily visible markers of DNR status (i.e., bracelets) that are available with the consent of a physician (Smith & Lo, 2012). While items such as bracelets are helpful in such cases, it is important that they be available only after a discussion with a medical provider, as serious consequences can obviously result from this decision. In addition, having a standardized marker of DNR status can assure first responders that they should in fact not attempt resuscitation, as they may similarly face serious consequences for making the wrong decision. It is also important that these markers be easily removable should the patient change their preferences regarding DNR status. Unfortunately, there are documented cases (Cooper & Aronowitz, 2012) of individuals choosing to tattoo life-sustaining orders on their bodies, and this may have serious unintended consequences for both the patient and care providers.

Finally, Study Three examined medical aid in dying, an end-of-life option that is becoming increasingly common on both a national and international level. While neither health literacy nor death exposure was predictive of support for the legalization of PAD in Study Three, high functional health literacy was significantly associated with more favorable attitudes towards PAD. This emphasizes the importance of being aware of health literacy when considering end-

of-life care preferences, as this may impact future care choices. As individuals with high functional health literacy have been shown to prefer shared decision-making compared to a paternalistic model of healthcare (Muscat et al., 2016), this may explain why there was no relationship between aggressiveness of end-of-life care choices and functional health literacy in Study Two. Given that slightly less than half of Oregon adults who receive lethal prescriptions from their physicians choose to utilize these medications (Oregon Health Authority, 2020b), this suggests that PAD may ultimately be viewed as an issue of autonomy and control. While collaborating with physicians to receive and fill a prescription for a lethal medication allows patients the option to voluntarily end their life of their own volition, life-sustaining orders listed in an advance directive will only be followed when an individual loses the autonomy to make their own medical decisions and becomes reliant on others to implement these interventions (or lack thereof) for them.

As PAD is currently legal in only ten U.S. jurisdictions, the Geriatrics Clinic patients in Study One do not reside in states in which PAD is an option. However, understanding their opinions and preferences regarding this topic may help to provide a broader ethical understanding of how older adults, many with serious chronic medical conditions, residing in the Deep South view PAD. Despite this treatment choice being unavailable in this region, this end-of-life option is becoming increasingly utilized, and global trends suggest that this will continue. A recent review of randomly-sampled death certificates within Belgium and the Netherlands (Dierickx et al., 2020) found that some form of medical aid in dying was involved in approximately one out of twenty adult deaths on an annual basis. While these countries have more liberal laws regarding medical aid in dying compared to the United States, including the legalization of euthanasia and the ability to express this preference via an advance directive (De

Vleminck et al., 2015), increasing utilization on an international level may lead to subsequent greater acceptance within the U.S. Therefore, it is necessary to continue to monitor and understand the views and opinions of U.S. adults towards medical aid in dying.

General Limitations

It must be mentioned that the majority of participants in all three studies were NHW and female, indicating a lack of diversity. Despite this, racial/ethnic discrepancies were observed in terms of functional health literacy in both Geriatrics Clinic and community-dwelling participants, with NHW participants having significantly higher scores on the NVS than African American participants. While it has previously been documented that African Americans are at risk for low health literacy (Kutner et al., 2006), identification of barriers is particularly salient to eliminate this discrepancy. This may include issues such as systemic segregation and historical mistreatment by the healthcare system (Muvuka et al., 2020), and physicians may be particularly prone to overestimating levels of functional health literacy in African American patients compared to NHW patients (Kelly & Haidet, 2007). An important focus of future work will be to eliminate these discrepancies, as interventions to improve functional health literacy and engagement with advance care planning may have a significant impact on both quality of life and receiving desired care at the end of life.

Finally, the self-selecting effect of participants in Studies Two and Three must be acknowledged. Both younger and older adults in these samples were able to find and engage with the MTurk platform, as opposed to Study One participants, who were patients presenting to regular primary care appointments. As with any sample, it is difficult to generalize results to a wider population, but the older adults who chose to participate in Studies Two and Three may be particularly literate in terms of technology. However, given the COVID-19 pandemic, it may

become increasingly common for researchers to utilize online platforms when conducting studies, which creates the risk that racial/ethnic minorities, older adults, and individuals with low socioeconomic status or health literacy may be excluded from research (Lourenco & Tasimi, 2020). It is hoped that this technology will become increasingly accessible as the world adjusts to a “new normal.”

Future Directions and Conclusions in the Context of COVID-19

All data collection for Studies Two and Three took place in June 2019, well before the emergence of COVID-19. Given the deaths associated with the subsequent pandemic in the United States, it is estimated that, even given a fairly conservative estimate of projected deaths, several million U.S. residents will lose a first degree relative (Verdery et al., 2020). While the current study assessed for death exposure in a community sample of U.S. adults, it is likely that many individuals have since experienced an increase in death exposure, and possibly fear of death, whether through personal losses or media coverage. As an additional complication, the potential inability to be present with relatives before or during death or hold funerals due to COVID-19 restrictions may cause individuals to react to the death of a loved one in a different way (Vigo et al., 2020) compared to when data was collected in 2019. While death exposure was not found to relate to end-of-life care choices or having an advance directive in Study Two, increased death exposure and subsequent awareness of mortality and fear of death related to the current exceptional circumstances may potentially impact approaches to advance care planning and may warrant further study.

In addition to changes in death exposure, there is now an increased focus on health literacy as a result of COVID-19 (Paakkari & Orkan, 2020). As this is a highly communicable disease, precautionary health behaviors are recommended at a societal level to slow community

spread. Unfortunately, individuals are often required to evaluate complicated medical information due to widespread misinformation and competing messages from sources such as social media and public officials, and this may be particularly problematic for those with low health literacy (Abdel-Latif, 2020; Abel & McQueen, 2020). This may result in individuals acting in unsafe ways, which has potentially serious public health consequences. As demonstrated in all three studies, low or inadequate functional health literacy continues to be present in a significant portion of U.S. adults and may be especially prevalent in community-dwelling older adults and racial/ethnic minorities. As older adults and members of minority communities have been shown to be at-risk for heightened complications or mortality due to COVID-19 (Bhopal, 2020; Sinclair et al., 2020), interventions within these groups may be vital. As demonstrated in Study One, functional health literacy can be quickly ascertained through brief screenings, and this practice may allow physicians to identify and intervene with individuals who are at-risk for unsafe behaviors in the context of COVID-19.

Health literacy was significantly associated with palliative care knowledge in Study Two, and the COVID-19 pandemic is increasingly requiring families to make urgent and difficult medical decisions for relatives (Block et al., 2020). Unfortunately, this is made even more challenging if advance care planning conversations have never taken place. Multiple authors (i.e., Block et al., 2020; Sinclair et al., 2020) have suggested that advance care planning discussions and documentation should occur in any available medical setting at this time, rather than being limited to more traditional palliative, oncology, or primary care settings. Even if patients do not have an advance directive, simply having these conversations with family members and providers can help establish values and contribute to patient-centered care (Hopkins et al., 2020). While participants in Study Two were relatively healthy, only 17.9%

reported having an advance directive on file at the time of data collection. This represents a potentially serious barrier to public health and receiving desired care at the end of life, particularly as medical providers are required to provide the highest level of life-sustaining care in the absence of clear documentation (Pearse et al., 2019).

A recent review (Portz et al., 2020) demonstrated that the creation of advance directives has rapidly increased in 2020, particularly when patients are able to document preferences through an online portal. Unfortunately, while more adults may be engaging in advance care planning, social distancing and other public health requirements may make it more difficult to access necessary services such as notaries (Block et al., 2020), and engagement with an online medical portal requires a certain level of health literacy and socioeconomic resources. Given the disproportionate impact that COVID-19 has had on minority communities (Bhopal, 2020), many of whom were already lacking healthcare resources, this represents a significant barrier to increasing advance care planning in at-risk individuals under the current circumstances.

Finally, the role of palliative care in the context of COVID-19 must be acknowledged. While PAD is not necessarily an option for patients in the United States suffering from this disease (i.e., individuals must be in the last six months of life and able to self-administer fatal drugs), many patients and their families are now faced with difficult choices regarding end-of-life care. This is made particularly trying by isolation procedures in which families cannot be with their loved ones during the dying process, regardless of the underlying condition (Wynne et al., 2020). This creates inherent ethical dilemmas, and it may be difficult to balance the needs of an individual (family presence near death) versus the needs of a population (mitigation measures to decrease the spread of COVID-19). Regardless, situations such as these emphasize how important it is that all persons be treated with respect and dignity at such times, regardless of

factors such as ethnicity, race, gender, or age. Disparities in access to palliative care are highlighted under such circumstances, and more work is needed to ensure that all individuals have access to adequate healthcare at these times.

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APPENDIX A



May 20, 2019

Amy Albright
Psychology
College of Arts & Sciences
Box 870348

Re: IRB # EX-19-CM-081: "An Exploration of Health Literacy, End-of-Life Care Preferences, and Death Exposure"

Dear Amy Albright:

The University of Alabama Institutional Review Board has granted approval for your proposed research. Your application has been given exempt approval according to 45 CFR part 46. Approval has been given under exempt review category 2 as outlined below:

(2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:

(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects

The approval for your application will lapse on May 19, 2020. If your research will continue beyond this date, please submit the annual report to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Sincerely,

T. Myles, MSM, CPM, CIP
Director & Research Compliance Officer

APPENDIX B



Office of the Vice President for
Research & Economic Development
Office for Research Compliance

January 9, 2020

Rebecca S. Allen, Ph.D., ABPP
Board Certified in Geropsychology
Professor of Psychology
Alabama Research Institute on Aging
The University of Alabama
Box 870348

Re: IRB Protocol # 14-005-ME-R6
"The University of Alabama Geriatrics Clinic Patient Data Collection Project"

Dr. Allen:

The University of Alabama Institutional Review Board has granted approval for your continuing review application. Your continuing review application has been given full board approval according to 45 CFR part 46.

The approval for your application will lapse on January 8, 2021. If your research will continue beyond this date, please submit a continuing review to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Good luck with your research.



J. Grier Stewart, MD, FACP
Medical IRB Chair

APPENDIX C
NEWEST VITAL SIGN

For the following questions, please refer to the picture below. Please **DO NOT** use a calculator. This information is on the back of a container of a pint of ice cream.



The image shows a Nutrition Facts label for ice cream. The label is set against a light blue background. It includes the following information:

Nutrition Facts	
Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories	250
Fat Cal	120
%	
Total Fat	13g 20%
Sat Fat	9g 40%
Cholesterol	28mg 12%
Sodium	55mg 2%
Total Carbohydrate	30g 12%
Dietary Fiber	2g
Sugars	23g
Protein	4g 8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

1. If you eat the entire container, how many calories will you eat? (Enter number only)
2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? (Enter number only)
4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? (Enter number only)
5. Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream? If no, why not?

APPENDIX D
END-OF-LIFE CARE PREFERENCES

You have the right to make decisions about the health care you get now and in the future. An advance directive is a written statement you prepare that expresses how you want medical decisions made in the future should you not be able to make them yourself.

1. Do you currently have a legal advance directive?
 - A. Yes
 - B. No
 - C. Unsure

Imagine that you are asked to make decisions about the medical care that you would desire at the end of life. Please answer the following questions about the **hypothetical** end-of-life care you would desire for yourself **at this moment**. Please note that your answers on this survey are **NOT** legally binding in any way and **are not** considered to be an advance directive.

1. Cardio-Pulmonary Resuscitation (CPR) involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

If you had no pulse and/or were not breathing, which of the following would you prefer?

- A. Attempt Cardio-Pulmonary Resuscitation (CPR)
 - B. Do not attempt resuscitation (allow natural death)
2. Intubation and Mechanical Ventilation refers to placing a tube down the patient's throat and connecting to a breathing machine that pumps air in and out of the lungs.

Which of the following options would be most consistent with your wishes?

- A. Intubation and long-term mechanical ventilation, if needed
 - B. A trial period of intubation and mechanical ventilation
 - C. Do not intubate (do not place a tube down the throat)
3. When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach, or fluids can be given by a small plastic tube (catheter) inserted directly into the vein (IV).

Which of the following options would you most prefer for IV fluids?

- A. No IV fluids
- B. A trial period of IV fluids

Which of the following options would you most prefer for artificial nutrition via a feeding tube?

- A. No feeding tube
- B. A trial period of feeding tube
- C. Long-term feeding tube, if needed

4. Which of the following options would be most preferable regarding transfer to a hospital or future hospitalizations?

- A. Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled
- B. Send to the hospital, if necessary

5. Which of the following options most closely reflects your preferences regarding the use of antibiotics?

- A. Do not use antibiotics (use other comfort measures to relieve symptoms)
- B. Determine use of antibiotics if infection occurs
- C. Use antibiotics to treat infections if medically indicated

APPENDIX E
DEATH EXPOSURE SCALE

Everyone experiences different amounts of loss and death during their lifetimes. Please use the scale below to respond to these 3 questions regarding your own experience. You may use any number from 1 (=none/not at all) to 10 (=very, very much). Select the number that is true for you.

1	2	3	4	5	6	7	8	9	10
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How much death—for example, the deaths of your family, friends, and loved ones—have you experienced:

1) During your entire life?

1 2 3 4 5 6 7 8 9 10

2) When you were a child (less than 16 years old)?

1 2 3 4 5 6 7 8 9 10

3) During the last 6 months

1 2 3 4 5 6 7 8 9 10

APPENDIX F
PALLIATIVE CARE KNOWLEDGE SCALE

1. A goal of palliative care is to address any psychological issues brought up by serious illness.
True; False; I don't know
2. Stress from serious illness can be addressed by palliative care.
True; False; I don't know
3. Palliative care can help people manage the side effects of their medical treatments.
True; False; I don't know
4. When people receive palliative care, they must give up their other doctors.
True; False; I don't know
5. Palliative care is exclusively for people who are in the last 6 months of life.
True; False; I don't know
6. Palliative care is specifically for people with cancer.
True; False; I don't know
7. People must be in the hospital to receive palliative care.
True; False; I don't know
8. Palliative care is designed specifically for older adults.
True; False; I don't know
9. Palliative care is a team-based approach to care.
True; False; I don't know
10. A goal of palliative care is to help people better understand their treatment options.
True; False; I don't know
11. Palliative care encourages people to stop treatments aimed at curing their illness.
True; False; I don't know
12. A goal of palliative care is to improve a person's ability to participate in daily activities.
True; False; I don't know
13. Palliative care helps the whole family cope with a serious illness.
True; False; I don't know

APPENDIX G
ATTITUDES TOWARDS PHYSICIAN-ASSISTED SUICIDE

“Medical assistance in dying provides patients, who may be experiencing intolerable suffering due to an incurable medical condition, the option to end their life with the assistance of a medical provider.”

Please use the following options:

Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree

1. Medical assistance in dying violates the physician’s Hippocratic oath (“First do no harm”).
2. Legalizing medical assistance in dying for terminally ill patients would place other vulnerable people (e.g., the elderly, disabled people, people suffering from mental illness) at risk.
3. Terminally ill patients should have the fundamental right to die when, how, and where they want.
4. Physicians should have the legal right to end the life of a competent person with a terminal illness if he or she requests it.
5. Legalizing medical assistance in dying would have a negative effect on the provision of hospice/palliative care services and programs.
6. Medical assistance in dying demeans the value of human life (i.e., sends the message that it is better to be dead than sick).
7. Medical assistance in dying would allow terminally ill patients to die with dignity rather than suffer indignities and loss of control brought on by their illness.
8. Medical assistance in dying would lead to a weakening of patient–physician trust (i.e., would undermine patients’ confidence in their physician).
9. Terminally ill patients experiencing intractable pain and suffering should be allowed to end their lives with the assistance of a physician.
10. Medical assistance in dying should **not** be a part of quality end-of-life care for terminally ill patients.
11. All possible measures should be taken to preserve the sanctity of human life.
12. Effective hospice/palliative care negates the need for Medical assistance in dying; if effective hospice/palliative care services and programs were available to all Americans, Medical assistance in dying should not be made a legal option for terminally ill patients.
13. Quality of life is a more important consideration in end-of-life decision making than quantity (or length of life).
14. Legalizing medical assistance in dying would free up physicians’ and nurses’ time to work on savable patients.
15. Terminally ill patients might choose medical assistance in dying for wrong reasons (e.g., undiagnosed clinical depression, not wanting to be a burden to their families).

APPENDIX H
CASE VIGNETTE

Please read the following paragraph carefully:

Mr. Smith is an elderly man with advanced, incurable cancer. His condition has declined to the point where he is bedridden, unable to care for himself, and requires large doses of pain medication to relieve his pain. He feels that the burden of his disease has become unbearable. He has been told he has at most six months to live. He would like, with the aid of his physician, to end his life painlessly and quickly. It has been determined that he is mentally competent.

Mr. Smith asks his physician to prescribe medication that can be taken to end his life. The physician agrees to this, and prescribes the lethal medication. Mr. Smith takes the medication and dies shortly thereafter.

1. This is a case of medical aid in dying. Setting aside the question of the legality of such an act, do you think the physician's actions were ethically justified?

1 (not at all ethically justified) and 2, 3, 4, 5, 6, 7 (completely ethically justified)

2. Do you think such actions on the part of the physician should be legal under certain well-defined circumstances?

1 (should not be legal) and 2, 3, 4, 5, 6, 7 (should be legal)

3. Which, if any, of the following statements describes important reason(s) why you think such actions should not be legal.

Such actions are against my religious beliefs.

Good palliative care should render such actions unnecessary.

Physicians' participation in killing patients is always wrong.

Suicide is always wrong.

There is a slippery slope in that there would be too many possibilities for abuse if such actions were legal.

Other _____

4. Which, if any, of the following statements describes important reason(s) why you think such actions should be legal.

Such actions relieve suffering.

Patients have a right to die as they wish.

Physicians should not abandon their patients even if it means assisting in their death.

Such actions will save money for the health care system.

Such actions are merciful.

Society must accept death as a natural part of life.

Other _____

APPENDIX I
DUKE UNIVERSITY RELIGION INDEX

1. How often do you attend church or other religious meetings?
 1. Never
 2. Once a year or less
 3. A few times a year
 4. A few times a month
 5. Once a week
 6. More than once a week

2. How often do you spend time in private religious activities, such as prayer, meditation or Bible study?
 1. Rarely or never
 2. A few times a month
 3. Once a week
 4. Two or more times a week
 5. Daily
 6. More than once a day

Please answer the following questions:

- 1 = Definitely not true
 - 2 = Tends not to be true
 - 3 = Unsure
 - 4 = Tends to be true
 - 5 = Definitely true of me
-
3. In my life, I experience the presence of the Divine (i.e., God)
 4. My religious beliefs are what really lie behind my whole approach to life
 5. I try hard to carry my religion over into all other dealings in life