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Applying Virtue Ethics: An Argument in Support of Advance Directive Cogitation Following the Death of a Spouse

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Applying Virtue Ethics: An Argument in Support of Advance Directive Cogitation Following the Death of a Spouse

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B.S., Emory University, 2018

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An abstract of
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Abstract

Applying Virtue Ethics: An Argument in Support of Advance Directive Cogitation Following the Death of a Spouse

By Kora Dreffs

Advance directives are documents that help to articulate end-of-life wishes, but are not utilized as readily as they could be. There are certain factors that help to predict whether or not one may have an advance directive. Some of the most salient include age, quality of relationships with others, marital status, and race. In the format of an interview of institutionalized persons, this pilot study asked whether or not bereaved persons update, or complete for the first time, an advance directive document following the death of a spouse. No participants in this study reported completing or updating an advance directive document following the death of their spouse. Following this finding, the project pondered whether and how a virtue ethics framework can provide meaningful guidance and motivation for the recently bereaved to attend to these pressing end-of-life care decisions. Using a virtue ethics lens, this thesis will provide a few examples of possible pathways to empower bereaved spouses to confirm that their advance directive documents, or lack thereof, reflect their current values. Ultimately, this study revealed three avenues to operationalize the reexamination of advance directives. Those include hospice bereavement programs, legal offices, and funeral homes.

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Chapter 1: Advance Directives and This Project

Though an advance directive creates a legally binding document to establish end-of-life wishes, they are not used as readily as they could be. In fact, less than 1/3rd of adults in the United States have an advance directive document in their medical records [1]. When U.S. adults were asked directly in a survey whether they had an advance directive, 73.7% answered that they did not [2]. Yet, 67.8% of these same adults "reported having concerns about end of life care" [2]. These concerns may or may not ever be addressed, as in 2017, 29.8% of deaths in the United States occurred in a hospital, and 20.8% of deaths occurred in a nursing facility [3]. In these locations, patients are "often in the context of aggressive high-technology treatment, even though most people, when asked, would prefer to die at home" [4]. If over 2/3rds of U.S. adults have concerns about their end-of-life treatments, then it seems that more than 1 in 3 of them should have a care plan in order. The problem is that 24% of these surveyed adults "don't know what advance directives are" in the first place [2]. This chapter will first provide a brief history on advance directives with definitions of some key terms, and will then examine various factors related to advance directive completion.

Advance Directive History

It has been 53 years since the first advance directive was proposed [5]. A human rights lawyer from Chicago, Luis Kutner, represented the Euthanasia Society of America and wrote an article detailing a proposal for the living will [6]. A living will is "a written directive describing preferences or goals for health care, or treatment preferences or willingness to tolerate health states, aimed at guiding future health care" [4]. However, the idea of living wills was not accepted until Abigail Van Buren (Dear Abby) began promoting them in her advice column [7]. After this periodic support displayed by the columnist, the first state to recognize living wills was

California in 1976 [5]. By the end of 1986, forty-one states adopted living wills [5]. With the increasing popularity of living wills, attention was also given to another form of advance directive: the durable power of attorney for healthcare [5]. This power allowed for an agent to make decisions on behalf of a patient if the patient ever were to become incapacitated [8].

There remains much variability in the scope of what is included in advance directives among different states. One 2002 study found that the only similarity in all 50 states as well as the District of Columbia was inclusion of "at least one statute-based advance directive document" [9]. In other words, all states offer at least one statutory document such as a living will or a durable power of attorney, but some states have multiple available advance directive documents. A problem with maintaining separate documents state-by-state is the lack of consistency in issues addressed. For example, some states may provide space to denote preferences for the administration of artificial nutrition and hydration, but others do not. In an attempt to simplify matters, a single "medical directive" was propositioned in 1989 [9]. While it was accepted by the American Bar Association in 1994, "most states continue to maintain separate documents and directives" [9]. The Georgia advance directive will be examined more closely, as this study obtained data at a nursing home in the state.

Georgia's current advance directive is composed of four separate parts. It contains sections for a living will, as well as a designation for a durable power of attorney for healthcare. Having both a living will and a durable power of attorney for healthcare is considered a combined statute, and was first introduced in 1991 by New Jersey [5]. Georgia adopted a combined statute on July 1st, 2007 [10]. This combined statute remains the current standard (as of April 2020) for a Georgia advance directive document. A current Georgia advance directive document is provided online at no cost by the Division of Aging Services as a part of Georgia's Department of Human Services [11].

Factors Related to Advance Directive Completion

Advance directive document completion has been linked to positive impacts amongst financial, medical, and social realms. For example, filling out an advance directive document has been shown to reduce the amount of money spent on treatment as persons near the end of life [12]. This statistic is important for healthcare in the United States as a whole, as in 1978 "28% of Medicare program expenditures were accounted for by 6% of persons who died during that year" [13]. This figure has held similarly in more recent years, as in 2006 Medicare spending for patients in the last year of their life accounted for 25.1% of total program expenditures [14]. Since a majority of the persons who are dying are older adults (65+), some treatments may only be increasing the longevity of their life, and not the quality of their final days [12]. By asking patients what their wishes are regarding their end-of-life care, unnecessary treatments can be bypassed, and money redirected to other facets of healthcare.

Advance directives are also viewed in a positive light when they allow patients to die a "good death" [12]. One study sought to define what a good death encompassed for patients, family members, as well as care givers [15]. Six themes were brought up frequently by interview participants, those being pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person [15]. Of specific note is the mention of clear decision making. This is because "an estimated 45%-70% of older adults facing end-of-life treatment decisions are incapable of making those decisions themselves" [12]. If clear decision making is important for persons to feel they died a good death, then these persons must account for the fact that they may not be able to articulate the end-of-life treatment and care they are interested in when the time arrives. Since advance directives allow persons to express their wishes prior to becoming unable to do so, it is important to educate patients on how these documents can help state their desires.

These documents are not just important for patients in their final days, but for the family and friends supporting the patient as well. Advance directives are "associated with better outcomes for family members, including reduced decision-making burden, and fewer anxiety and depressive symptoms" [12]. While compassionate care should be provided to the dying and is the highest priority in their final days, it has been found that these patients still wish to contribute positively to others [15]. If patients knew that documenting their end-of-life wishes may be of benefit to their family members, it may become more important for them to complete advance care planning. A program that has specifically been tied with support for the bereaved is hospice [12]. Being enrolled in hospice care results in bereaved family members having "reduced risks of mortality, depression, and traumatic grief" [12]. Hospice bereavement programs will be examined in more detail in the future directions section. Since patients note that a good death encompasses positive contributions to family, caregivers, and friends at the end of life, they should be educated on how documenting end-of-life wishes impacts their family members in a meaningful way.

It is unreasonable to expect that all persons will ever complete an advance directive document despite the positive benefits they may bring. For the persons that do not have any form of advance directive document, legislation has been passed [5]. These laws are found in the District of Columbia, as well as 44 states [5]. If no advance directive document is had, then "permissible surrogates, usually starting with spouse and a next-of-kin priority list" is created

[5]. There are wide-ranging differences among states regarding who constitutes next-of-kin, including the question as to whether or not a close friend or domestic partner can be in the mix [5]. Even if power is extended to some living relative, friend, or partner, “these laws also vary significantly in the scope of authority granted to surrogates and in the procedural formalities required in the decision-making process” [5]. While a next-of-kin may be identified and allowed to make decisions on behalf of the dying, these choices may not be representative of what the patient would want.

One study found that, in end-of-life scenarios, surrogates incorrectly report spousal preferences regarding cognitive impairment 13% of the time, and incorrectly report spousal preferences on physical pain 26% of the time [16]. If spouses are incorrectly reporting preferences regarding pain 1 in 4 times at the end of life, then it seems plausible that further removed next-of-kin will perform even worse at correctly articulating end-of-life preferences. Research suggests that “surrogates projected their preferences onto the spouse” [16]. This is an important consideration to keep in mind when persons choose to forego advance directives in hopes that their loved ones will be able to articulate their interests. It may not be possible for loved ones to forego their personal idea of end-of-life care in order to make decisions for the patient receiving the care. There are some additional cases where no advance directive document is found, and the person also has no friends or family. This is called an “unbefriended patient,” and leaves questions as to who may make decisions on their behalf [5]. Since there is no universal procedure in place for the United States, what happens to patients with no form of advance directive largely varies depending upon location.

With so many differences between states, it is not surprising that adults in the United States are unsure of what an advance directive is, or do not have one completed. One barrier to education and completion is that “patients often wait for their healthcare providers to bring up the subject, while many healthcare providers assume patients will bring up the subject” [17]. It is possible to argue that this burden to educate ought to be put on physicians’ shoulders. However, these physicians are just as immersed into American culture as the patients are. Even if they have more knowledge about the documents, the topic may feel just as taboo to discuss. On the same token, “healthcare providers operate under great pressure in a system that does not provide incentives or adequate training to discuss end of life options with patients and their families” [17]. One way to avoid this standstill is the passing of laws which require patients be counseled on advance directives by their care providers. One such law has been in place since the 1990s and helps raise awareness of advance directives to a certain subset of patients.

The United States Congress passed the Patient Self-Determination Act (PSDA) in 1990 [18]. This law states that nursing homes participating in Medicare or Medicaid must provide written information about the right to formulate and sign an advance directive [19, 20]. Following the passage of the PSDA, the percentage of persons with an advance directive document in a long-term care facility has been higher than that of the U.S. adult population as a whole [21]. In fact, the most recent national nursing home survey found that 65% of nursing home residents in the United States have at least one form of an advance directive [21]. This positive trend in advance directive completion among long-term care facility residents following passage of the PSDA demonstrates that counsel on these documents is a worthwhile endeavor. In relation to this project, since patients in nursing homes are more likely to have at least one end-of-life care document, this population serves as an excellent resource to learn about advance directives. There are other factors correlated with filling out an advance directive document, and the remainder of this chapter will be dedicated to looking at some of the most predominantly reported associations for completion or lack thereof.

First of all, there is a gradient associated with age as 77% of persons over the age of 85 in nursing homes have an advance directive, whereas only 36% of persons under the age of 65 have at least one form [21]. These trends are comparable to home health care patients. For home health care patients over the age of 85, 41% have at least some form of advance directive [21]. Yet, only 17% of home health care patients under the age of 65 have at least one advance directive document [21]. Another study, completed in Baltimore, Maryland, at five Kaiser Permanente health centers found that “patients 75 and older were twice as likely (odds ratio [OR], 2.0; 95% confidence limits [CL], 1.2 to 3.3) as those 65 to 74 to file a new advance directive” following education by health care providers [22]. For all of these patients taken together, “only one-third to one-half of all adults in the United States have completed advance directives, although rates are as high as 70% among adults aged 65+” [12]. Since older adults are the most likely to have advance directive documents, this population is a good target for researchers trying to learn more about their completion.

Another factor that is predictive of advance directive completion is said to be the professional relationships a patient holds with others. Health care providers are in a unique position to hold conversations surrounding advance care planning [23]. However, another group of professionals (attorneys) are more often cited as being utilized during advance directive document completion [24]. A study of a Veterans Administration outpatient clinic specifically noted the strong correlation found with attorney discussions [24]. The study randomly selected 255 patients, and completed a multiple logistic regression to compile the predicting factors [24]. This correlation between face-to-face visits with an attorney and advance care document completion has been published in other studies, as well, with a finding that “a visit to one’s lawyer to…complete one’s will often triggers the completion of related documents, including living wills and DPAHC appointments” [12]. The idea of visiting a lawyer being tied to completing advance directive documents will be returned to later in this thesis, as the data obtained in this study also support that hypothesis.

There are also personal relationship considerations that help predict completion of advance directives. Previous studies have found that positive relationships with family members are linked to the completion of advance directive documents [25, 26]. This literature was further expanded upon in 2017, noting that “people with supportive family relationships are more likely than those with troubled relationships to execute advance directives” [12]. Having these supportive relationships may be helpful in overcoming a noted phenomenon where “both patients and surrogates expressed concern that the other may not be ready and could even be harmed by engaging in advance care planning” [27]. This study, explicating the need for advance care planning discussions between family members, noted that not engaging in these conversations can lead to misunderstanding, and needs not being met by either patient or surrogate [27]. Stronger family ties may help to overcome this barrier, and lead more persons to complete advance directive documents.

Another paper states that “the primacy of the family emerged throughout the study, suggesting that advance directives may be a family issue rather than solely an individual one” [28]. While competent patients are responsible for their own advance directives, it is important for patients to discuss what end-of-life care they wish to have with their family. One study found that 71% of family members and patients agreed regarding CPR, and 68% agreed regarding ICU admission [29]. While these figures demonstrate a majority of patients are in agreement with their family regarding these decisions, there remains room for improvement. To reduce the pressure of patients and professionals, family members should also be encouraged to discuss what the patient's wishes are, and help ensure that the care the patient wants is provided. These types of conversations may help deepen family ties, as well as provide clarification on end-of-life wishes.

These personal relationships are a factor that can impact many persons. One study of 304 participants (recruited in physician offices and a senior center) found that "84% had one or more personal experiences or experience with others" of major illness or surgery and end-of-life care [30]. The results revealed that "having one or more experiences with others was associated with increased readiness to complete a living will and healthcare proxy, discuss life-sustaining treatment with loved ones and discuss quantity versus quality of life with loved ones and with physicians" [30]. This finding directly applies to the work of this thesis. By interviewing bereaved persons, they will have had at least one end-of-life experience during their spouse's care. If a similar correlation is found, interviewees in this project may be more apt to complete or update an advance directive document. Additionally, this experience may lead interviewees to be more comfortable discussing their end-of-life preferences. Therefore, interviewing bereaved widows/widowers may provide an increased opportunity to unveil a link between updating or completing advance directives following death of a spouse.

While personal experiences related to end-of-life care are widespread, it is important to note that these occurrences all impact individuals differently. Based on previous lived experiences, the exact same scenario could impact two persons differently, and shape separate responses. With this knowledge in mind, it may be important to provide "tailored, stage-specific interventions based on individualized assessments to improve advance care planning" [31]. Since persons must formulate advance directive documents about themselves, it is no surprise that their various life experiences can dictate what goals they have about their end-of-life care. It is important to understand the underlying needs and values each person has. By acknowledging certain beliefs or feelings, it may become evident what is important to address in a person's advance directive document. The idea of tailoring advance directive documents for individuals based on their priorities should be a main concern, and will be discussed further as it pertains to virtue ethics.

Another factor that impacts completion of advance directives can be found in whether or not a person is a widow or widower. Studies across the years have found that persons reporting to be widowed are more likely to have an advance directive document than those who are single or separated [24, 32]. Again, these data are promising for the purposes of this thesis. By interviewing bereaved spouses, there is an increased likelihood that these persons updated or initially completed an advance directive following the death of their spouse. This may help inform whether or not death of a spouse is correlated with updating or completing advance directive documents.

The correlation between widows/widowers being more likely to have an advance directive document can be further analyzed. One study utilized data from the Health and Retirement Study, which represented 2,279 community-dwelling couples following the death of a spouse [33]. This study found that widows and widowers were "less likely to have advance care planning when…[their]…spouse did not have advance care planning prior to death" [33]. However, amongst these widows/widowers, the likelihood of advance directive completion decreases when the deceased spouse did not have a document noting their end-of-life wishes. From this, the study authors hypothesize that advance care planning is a learned behavior, and persons with deceased spouses would be a good target group to educate for future planning [33]. That is, persons use their previous experiences to help determine whether or not they need an advance directive document. If a deceased spouse completed an advance directive, then that experience may lead the bereaved to have a document of their own. If completing these documents are not innate, then it will be impossible for persons to know they should complete them without education or observation of another individual utilizing the document. The authors concluded that their "results suggest that investigating an individual's experience with spousal death can meaningfully inform advance care planning" [33]. These spousal experiences with death may be viewed by the bereaved as positive or negative, but further research surrounding loss has shown that both good and bad experiences are related to completion of advance directive documents.

One cohort of data, from the New Jersey End of Life study, provided details of 253 adults from two New Jersey medical centers that recently lost a loved one [34]. These data showed "'positive' role model effects; persons who witnessed significant others' deaths that occurred at home, were free of problems associated with end-of-life care, and where advance directives were used are more likely to make end-of-life preparations" [34]. A better experience with the death of a significant other prompted persons to create advance directive documents of their own. However, the negative effect also plays a role, as "open-ended data showed that 19% cited others' deaths as the main trigger for their own planning, with most citing negative factors (pain, connection to machines, coma) that they hoped to avoid" [34].

Another study pulled data from the Wisconsin Longitudinal Study, and used the random 70% subsample of the 3,838 respondents asked about end-of-life planning [35]. There were three types of end-of-life care – a living will, a durable power of attorney for healthcare, or having informal discussions about end-of-life preparations [35]. In this sample, it was found that "having survived the painful death of a loved one was a significant predictor of all three types of end-of-life planning" [35]. Taken together, these various studies reveal that both positive and negative experiences related to the death of a significant other lead to increased completion of advance directive documents. These previous correlations make the bereaved a good target for advance directive research, because these individuals are more likely to complete advance directives following death of their spouse.

While relationships with significant others are related to completion of advance directives, it is important to consider how the patient views him or herself. One study conducted interviews of 23 persons from Pennsylvania, and found that persons were driven by a concern for self to complete advance directives [23]. In other words, persons are more likely to complete an advance directive document if they feel it may lead them to a self-determined acceptable quality of life. If persons do not feel they may receive end-of-life care that is in line with what they seek, then they will not take the time to complete an advance directive document. It makes sense, then, that persons with death anxiety are less likely to have some form of advance directive document [12]. If persons are anxious about death, they may feel overwhelmed when attempting to articulate what they believe to be an acceptable end-of-life care plan.

One well documented phenomenon is that non-white patients are less likely than white patients to have completed advance directive documents [12, 36, 37]. Exact statistics vary, "but most research finds that Whites are two to three times as likely as Blacks and Latinos to have an advance directive" [12]. However, it is important to note that discrepancies in filling out these documents has lessened in the last decade [12]. In part, this may be caused by a finding that for "adults under age 64…race gaps in advance directive use were negligible" [12]. This may be due to the very limited percentage of persons under this age that complete an advance directive document in the first place. This lack of documentation may lead to non-white patients not receiving the care they desire at the end of life [12]. It is important to note that this is not the only factor that may result in undesired care, but additional problems like bias, prejudice, racism, etc. will not be tackled in this thesis. A statistic of cancer patients found that "Blacks are one-third as likely as Whites to receive care that is consistent with their preferences" [12]. The lack of advance directive documents also impacts spending, as "medical expenditures in the last six months of life are considerably higher for Blacks and Latinos, relative to Whites" [12]. These expenditures are higher because "85 percent of these observed higher costs for Blacks and Hispanics are accounted for by their greater usage of intensive (and costly) invasive treatment" [12]. There should be increased efforts to educate all patients on the benefits of these documents to help increase compassionate and desired care at the end of life, as well as reduce the monetary burden for unwanted care.

Another explanation for patients being less likely to complete advance directive documents is due to religious beliefs that a higher power will control their destiny [12, 36, 38]. These ideations may stem from a viewpoint that "'God will decide'" when that person should die [12]. In this way, these persons believe that no documentation will be able to change the plans that God has in store for them. Studies demonstrate that persons with "Fundamentalist beliefs…who believe that the length of their life is in God's hands, who rate religion as 'very important,' and whose religious beliefs guide their behavior are less likely to do formal advance care planning" [12]. Regardless of a person's religious views, it is important to verify they understand what advance directive documents may do for them. This is because many religious persons "assume (incorrectly) that living wills limit rather than request treatment" [12]. These patients should not be kept from advance directive discussion due to strict religious adherence and belief that these documents are unnecessary, but rather be provided means to make their end-of-life wishes known in the context of their religious preferences. One such potential pathway is to utilize the "Five Wishes Document" where religious beliefs can be documented in addition to more traditional advance care planning choices [12]. Allowing a space for spiritual information to be documented may allow these highly religious persons to feel more comfortable filling out advance directive documents.

There are some barriers to providing advance directive education to persons. One reason is that persons with a lower education level are less likely to have advance directive documents [2, 12]. One explanation for this may be "the high literacy level of most advance directives and advance care planning health education materials (ie, beyond a 12th-grade reading level), despite an average 8th-grade reading level among US adults" [39]. Another barrier may be socioeconomic status and advance care planning, as "emerging research shows that older adults with lower levels of education, income, assets, and home ownership rates are less likely than their more advantaged counterparts to do formal advance care planning" [12]. This may be in part because of the strong correlation between completing advance care documents and visiting an attorney [12, 24]. If persons are not visiting attorneys to fill out a financial will, then there may not be a suggestion provided to also complete a living will. These problems contribute to each other, because persons are hesitant to complete advance directive documents if they do not understand what the treatments are that they are making decisions about [12]. Taken together, it becomes clear to see that various patterns emerge as to which factors may predict the completion or noncompletion of an advance directive.

Of the literature reviewed, all studies gathered information from non-institutionalized adults. Researching institutionalized adults seems like an important gap to explore, since nursing home residents are more likely to have advance directive documents than the general population. As of 2014, there were nearly 1.4 million current residents in nursing homes in the United States [40]. Within the next 20 years, the number of older adults will double [41]. This will likely be troublesome for long term care facilities, as "the largest growth…will be among the 'oldest-old,' who are disabled at the highest rates" [42]. In 2018, there were 8.9 million widows and 2.6 million widowers in the United States [43]. The author of this thesis performed a PubMed search, which revealed no published data that assess whether or not spousal illness and subsequent death causes nursing home residents to complete or update their advance directives.

Initially, the aim of this study was to determine whether or not widows/widowers considered completing or making changes to their advance directive documents following the death of their spouse. In other words, this research sought to determine if the interviewees made decisions to update or complete an advance directive in the context of their spouse's death. This initial goal is demonstrated by the phrasing and nature of the questions asked to study participants. However, as will be further detailed later, no bereaved persons made updates or changes to their advance directive documents. Since no changes were identified, it was inherently impossible to disentangle the answer to the initial question. This caused the goal of the project to shift, and use collected data to answer a separate, but related, question.

The purpose of this thesis is to establish whether, and how, virtue ethics can provide meaningful guidance and motivation for the recently bereaved to attend to pressing end-of-life care decisions. The primary objectives are trifold:

- Establish why virtue ethics is applicable to advance directive completion and reconsideration, as well as expound why virtue ethics is more suitable than other ethical frameworks or principlism.
- Apply a virtue ethics lens to the data obtained in this study in order to speculate on how best to empower bereaved spouses to verify that an advance directive document, or lack thereof, reflects their current values.
- Assess three industries that could help operationalize the reexamination of bereaved persons' advance directive documents following the death of their spouse.

Chapter 2: Ethical Considerations of Advance Directives

While advance directives can help persons make their end-of-life wishes known, they do not come without potential downfalls. Health care providers raise some of these concerns, for example when patients stipulate a wish in their advance directive which a provider may find futile in nature. Other concerns are brought about by the loved ones of patients, and the worry that they might disagree with the choices detailed in the advance directive. There are questions regarding the role of lawyers in helping to prepare advance directives, as they may provide improper explanations as to the possible treatment choices. However, the focus of this thesis revolves around the ethical considerations for bereaved spouses. For the remainder of this thesis, ethical considerations of caregivers, family members, or friends will take a back seat to bereaved spouses. The purpose of this chapter is to detail a theoretical framework which helps to examine ethical considerations of advance directives, then consider shortcomings of applying other theories or principlism by detailing some potential scenarios.

Virtue Ethics

Virtue ethics was articulated by a philosopher and theologian, Thomas Aquinas [44]. He described virtues as being “a good habit or a disposition that is productive or good” [44]. The definition of virtue has been further flushed out since Aquinas [45]. Now, a virtue is considered to be “a dispositional trait of character that is socially valuable and reliably present in a person” [45]. Overall, “the goal of virtue ethics is ‘to ensure that all individuals within a society flourish’” [46]. In part, it helps persons to flourish by bolstering meritorious character, which is “each person’s unique moral identity, or who a person is at the core of his or her being” [44]. Different values vary from person to person, and change across their lifespan [44]. External factors mold persons, as “ethnic, religious, social, and economic contexts affect our character and our own development of virtue” [44]. If individuals cultivate a life with a focus on the values most important to them, then virtue ethics would attest that those persons have a “right to live out the end of your life in a way that is consistent with your values” [46]. This would include making decisions that benefit a person during the most vulnerable part of their life, as they undergo the dying process. It is important to closely review virtue ethics as it pertains to advance care planning, as for vulnerable populations this framework may be advantageous [46]. There are certain virtues that have been noted to be of high potential impact to persons who are confronted with decisions as medical patients, and a few of those will be further detailed. Therefore, the four virtues that will now be further examined will be directly applicable to those in this study, as well as other bereaved spouses.

One virtue that may have applicability for patients is courage. Dr. Earl E. Shelp, a previous medical ethics professor at Baylor College of Medicine, presented courage as being an overlooked virtue important for both doctors and patients [47]. Being courageous “does not always take the same form in every context or role” [47]. That is, what may be considered a courageous act by one person may not necessarily be an exemplar of courage for all persons. There is no one scenario or example which proves the courage of a patient. However, Dr. Shelp proposes that being a courageous patient is not simply fighting off death for as long as possible, but rather viewing the end of life as an opportunity to learn about what it means to be human [47]. When persons consider advance directive documents in any capacity, they may demonstrate courage by contemplating what experience of dying they wish to undergo. This contemplation may help them “learn about the nature of human existence” [47]. For this reason, courage may be a virtue displayed by many patients in various capacities.

Three other virtues that may be beneficial to patients were proposed by Dr. Karen Lebacqz, a previous ethics professor at Pacific School of Religion. Dr. Lebacqz recommends the virtues of fortitude, prudence, and hope [48]. Fortitude is presented as the tenacity necessary to continue various pursuits amidst the various emotions that may envelop patients [48]. For example, this may include not becoming overwhelmed with fear about a current scenario, or completely succumbing to a diagnosis. Rather, it is "pursuing a vision of the future, perhaps not the one initially desired or intended, but still one consistent with established personal values and goals" [49]. With this is mind, fortitude may be applied to patients contemplating their advance directives and end-of-life care. Even with an upsetting diagnosis, patients may define their end-of-life wishes in a way that is still in line with their objectives via an advance directive. Having this document may help persons to push onwards, despite the other emotions surrounding the dying process.

Prudence was the second virtue proposed by Dr. Lebacqz. For patients, prudence is exercising sound judgment during illness [48]. Dr. Lebacqz claims that "patients learn about themselves and about the meaning of their lives from their confrontation with illness" [48]. Again, this may be applied to advance directives, as patients grapple with what may be in store for them during their dying process. By employing the virtue of prudence, patients will be "preventing over-confidence and/or foolhardiness" [49]. Making decisions without demonstrating hubris or recklessness may allow persons to present what is most important to them during their end-of-life care. Therefore, prudence is a virtue that may be exercised by persons completing, updating, or reviewing advance directives.

A third virtue proposed by Dr. Lebacqz was hope. Dr. Lebacqz states "hope involves perfecting the will to trust in the attainment of the end…that when we perceive the real and it turns out to be terrifying, we do not despair" [48]. Without hope, patients may feel as if no treatments or plans are useful to them. A lack of hope "may be reduced to that Shakespearean cliché: 'full of sound and fury, signifying nothing'" [49]. In these scenarios, patients may live out their days in a way that is not fitting to their wishes. A virtuous patient will remain hopeful and have trust throughout their human journey towards death.

While the virtues of courage, fortitude, prudence, and hope have been highlighted, those are not the only virtues that are important when considering end-of-life decisions and completing advance directive documents. However, these illustrative examples will be on display by patients considered virtuous [49]. Virtue ethics also holds that "society has a duty to its citizens to enable them to develop these virtues and should, therefore, provide the best medium for their development" [49]. In the conclusion, this thesis will provide three avenues that may be suited to empower patients to develop these virtues. Specifically, the opportunities mentioned will be able to empower bereaved spouses, like those interviewed in this study.

This thesis will assume the premise that virtue theory is most applicable to bereaved patients regarding their advance directives and end-of-life care. Upon taking this stance, it is important defend why this theory is a better alternative than other frameworks or principlism before turning to the specifics of this study.

Utilitarianism

Utilitarianism holds that there ought to be "an objective assessment of everyone's interests and an impartial choice to maximize good outcomes for all affected parties" [45]. In society, utilitarianism may be beneficial to help support the greatest number of people. However, as it is applied to advance directives, it raises red flags as to whether or not the dying person will be protected [46]. In other words, utilitarianism may lead persons to make end-of-life decisions "on the basis of what will bring the most happiness to the family members, who usually represent a larger number of voices than the vulnerable person him- or herself" [46]. For example, take a hypothetical patient with chronic kidney failure. Let us make clear that there are no strong ethical considerations beyond those of the patient and their family. That is, no other persons will be impacted by this patient undergoing dialysis such that it would produce negative outcomes for unnamed parties. In this instance, let us pretend the patient wishes to forego dialysis. While the dialysis may extend their life, the patient feels it will bring unnecessary suffering. Let us also pretend that the patient has 30 family members. None of which believe that the suffering caused by dialysis will be greater than the joy they receive from having the patient live a longer period of time. In a utilitarian lens, even if this one patient will suffer, an argument will be made for that patient to undergo dialysis if their extension of life will provide joy to 30 family members. In this way, the positive outcome for the family members will trump the wishes of the dying.

Applying a virtue ethics lens to this same scenario will result in a different analysis. Even though 30 family members may retain happiness with the prolonged life of their loved one, the net amount of good vs. suffering will not be in direct competition. Instead, virtue ethics would highlight a need for prudent decision-making by the patient, despite being only one voice. While virtue ethics would encourage the patient to showcase compassion towards the viewpoints of the family members instead of simply dismissing their feelings, the 30 opinions will not ultimately override that of the patient. Since advance directives are a means to ensure the wishes of the dying are met, this theory better allows the voice of the patient to hold weight when compared to the persons surrounding them. While this was only one applied example, the same logic would hold true for other dying patients with end-of-life wishes that differ from those around them. For this reason, virtue ethics seems more equipped to handle end-of-life treatment preferences than utilitarianism.

Deontology

Kantian theory is “a theory of duty holding that some features of actions other than or in addition to consequences make actions right or wrong” [45]. Therefore, deontology departs from utilitarianism in the sense that it has more of a focus on determining whether or not an action itself is justified, as opposed to considering the consequences of an action. In this theory, “there is little room for subjective decision making…determining what makes the most sense when the medical knowledge or advice is pinned against the patient’s established wishes from the care directive” [46]. This theory was founded with the ideation that there are right and wrong actions. For instance, that lying is not permissible. If lies were to be accepted, then there would be no such thing as a lie. This would be because lies would no longer be considered departures from the right way to act, but become a new standard. Kantian theory comes with a set of rules that are to be followed in order to live out a moral life.

One consideration with deontological theory results when the set of accepted rules directly conflicts with what a patient wishes for at the end of their life. To help put this theory in perspective, let us ponder a case that can be related to the underlying ideas of this thesis research. Say, for instance, there is a bereaved person that went through much mental pain and misery following the death of their spouse. Their spouse completed their advance directive such that they wished to have artificial nutrition and hydration if they became unable to articulate their wishes following the diagnosis of a terminal illness. In this scenario, the bereaved person of interest also filled out their advance directive in the same way. The parties discussed the scenario and, following an ideation that withholding medical treatment is akin to killing, both decided that they wished for artificial nutrition and hydration at the end of life. However, during the death of the spouse, the person of interest was miserable watching a painful death be extended by artificial measures. The bereaved may now wish to update their advance directive so as to not obtain artificial nutrition and hydration. Kantian theory might cause this person internal struggle, as this change conflicts with their previously held duty. Even with a claim that one's understanding of the duties have changed, justifying an update, this does not eliminate the internal battle. This may put persons at a crossroads between doing what they feel is best, and following a previously held rule. In a scenario where an advance directive document ought to be changed to better reflect true wishes, deontological theory falls short. Kantian theory can cause internal strife, whereas virtue ethics will help to empower the bereaved to update their document as they see fit. Not only would virtue ethics provide persons room to make changes if they wish to do so, but also respect the decision to maintain the same document.

Virtue Ethics vs. Other Frameworks Summary

While both utilitarianism and deontology are well-respected ethical frameworks, neither seem to empower bereaved spouses planning their end-of-life care in the same manner as virtue ethics. Utilitarianism places too much emphasis on the wellbeing of the many, as opposed a single person completing their advance directive document. When completing advance directives, this process should be personalized and focus on the person whose wishes are being documented. In this way, virtue ethics is superior to utilitarianism in providing power to bereaved spouses. On the other hand, Kantian theory provides a set of rules that ought not be broken. A strict observance to these rules may be off-putting to some persons who feel that their priorities change as they face various scenarios and age. Virtue ethics concedes that values can change, while also respecting the wishes of those that remain steadfast in their duties. Virtue ethics helps to empower the bereaved to make the decisions best for them, and can justify revisiting advance directive documents as many times as necessary to reflect current priorities. Advance directive documents should not be bound to a certain set of ideals that are unmoving for all persons, but rather be an evolving system that emboldens individuals. Therefore, virtue ethics is more widely applicable to bereaved spouses making decisions on their end-of-life care than deontology. Since virtue ethics provides a structure to protect the voice of the one person an advance document represents, as well as maintain applicability to the values of many diverse individuals, this thesis will maintain it is the best framework with which to enable bereaved spouses planning their end-of-life care. Now, the focus will turn from deontology and utilitarianism to principlism.

Principlism

Thomas L. Beauchamp and James F. Childress are American philosophers that founded principlism. They designate four principles to guide biomedical ethics – autonomy, nonmaleficence, beneficence, and justice [45]. To make clear how these principles fall short when discussing end-of-life care while utilizing advance care planning, various circumstances will be considered. These examples will not be completely exhaustive of all potential scenarios resulting from advance directive completion, but demonstrative possibilities will be illustrated.

Autonomy

The idea of autonomy was first described in The Belmont Report, then further elaborated on by Beauchamp and Childress [50]. Autonomy has a broad definition, but “is, at minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” [51]. In order for a decision to be autonomous, three criteria must be met. Those include the action being authentic in nature, free from external interferences, and the agent performing the action being competent and informed [50]. Autonomy has helped patients by freeing them from paternalism, empowering them by giving them decision-making capability, and helping them defend their rights [50]. Bioethics has long held that, under autonomy, persons ought “be permitted to make their own decisions about what medical treatment they want and do not want” [52]. However, an instance in which autonomous decision-making may be questioned is when patients request treatment that is considered to not be beneficial, or futile.

The word futile, itself, “’cannot be meaningfully defined’” [53]. However, a working definition for futility is “’an action, intervention, or procedure that might be physiologically effective in a given case, but cannot benefit the patient, no matter how often it is repeated’” [53]. This problem can arise between patients (or their medical decision-maker) and the team treating them. There are four specific instances in which futility has been described by ethicists. Those instances are described as physiological futility, imminent-demise futility, lethal-condition futility, and qualitative futility, and were articulated by ethicists Baruch Brody and Amir Halevy [53]. Qualitative futility refers to a treatment that works, but will result in a poor quality of life, therefore making the treatment unwarranted [53]. Lethal-condition futility is applied to terminal persons, where treatment is unrelated to their condition, and will not save them from an imminent death [53]. Imminent-demise futility describes the patient being near death regardless of any proposed treatment, therefore making it useless [53]. Lastly, physiological futility is reserved for treatments that do not work as intended, with no reason to continue to use them [53] and help to justify a care provider's decision to not provide further treatment [54].

There are critiques that the notion of autonomy can be taken too far as in justifying futile treatment. In instances of futile treatment, patients are often met with "a very physical and emotionally demanding experience, which affects one's ability to choose" [50]. If the ability to choose is impacted, persons may not be making choices which are truly authentic in nature. Since authenticity is necessary for an act to truly be autonomous, some persons experiencing these draining experiences may be unable to fulfill this requirement in acting autonomously. While this is just one illustrative example, a focus on the principle of autonomy to guide ethical decision-making is a "nearly elusive vision" [55]. In these scenarios, virtue ethics may provide a more reasonable path forward, by stipulating that the patient in question ought to manifest the virtue of prudence. This type of sound judgment may help individuals develop more realistic expectations for their care plans and end-of-life goals. While this is not to say that patient autonomy should be pushed aside, it is important to note that relying on this principle alone may not lead to patients making end-of-life decisions that are in line with their objectives. Instead, empowering patients to develop and rely on virtues like prudence will allow them to be realistic while still making meaningful choices.

Nonmaleficence and Beneficence

Nonmaleficence, simply put, is not harming the patient [45]. While this principle seems quite applicable to advance care planning, it is important to note that it revolves around the actions of a care provider. That is, this principle dictates that care providers should do everything in their power to not intentionally harm a patient.

Beneficence builds on nonmaleficence, and ensures that not only are patients not harmed, but that good is performed on their behalf [45]. Again, while this principle may be applicable to advance care planning, it focuses on those who are helping the patient. Care providers are encouraged by this principle to do good for their patients whenever possible.

These two principles are important for patients, as they guide caregivers to do no harm while actively promoting good for those they serve. In an end-of-life setting, these principles help caregivers to make choices in line with what the patient desires. However, these principles fall short by not empowering patients as effectively as virtue ethics. Virtue ethics mandates that each person should cultivate meritorious virtues, unlike these principles which focus on actions of the caregiver. If we truly wish to provide patients with a means to make sure their advance directive documents, or lack thereof, reflect their current values, the ethical systems in place must be directly relevant to the target population.

Justice

Lastly, the principle of justice is described as equality and fairness among persons [45]. An important distinguishing factor with justice is that it is the only principle which is also considered to be a virtue [56]. The difference between justice as a principle and a virtue is that "justice as a principle requires that we give each what is their due. Justice as a virtue is a habituation of giving others their due" [56]. This differentiation is important, because how we define justice will change the reasons for which justice is applied. Virtue ethics and a habituation of justice is said to be continually loving others instead of simply loving the self [56]. When there is not a habitual approach towards justice, and it is simply giving other people what they are due, “justice primarily becomes an obligation-based system that promotes self-interest” [56]. This thesis will concede that the result of applying justice as a principle or justice as a virtue will be the same action with different motivation. For that reason, there will be no speculation as to whether a principled approach to justice or virtuous approach to justice is superior.

Virtue Ethics vs. Principlism Summary

Following the discussion of the various principles, it is important to summarize why virtue ethics, as a whole, is more robustly applied to advance directives and end-of-life care for patients than the various principles taken together. At first blush, autonomy seems like a reasonable principle to apply to advance directive documents for bereaved spouses. This is because autonomy emphasizes individuality, and making treatment choices best suited for each person. However, relying on just this principle is not always possible if persons cannot meet the three criteria necessary for making an autonomous decision. End of life decision-making may be especially taxing for some persons. Thus, they might not make authentic choices, which is not autonomous. Virtue ethics, on the other hand, stresses that if persons have been habitually making virtuous choices, their reaction to a situation will be representative of their best self. In other words, an emotionally taxing situation will not cause persons to crumble under pressure and make inappropriate decisions, but habit will take over. Next, the principles of nonmaleficence and beneficence may be useful in end-of-life care, but are more applicable to the actions of care providers than patients. Therefore, virtue ethics is more robustly applied to the persons of interest in this thesis. Lastly, justice is both a principle and a virtue. No argument was made to claim that the virtue of justice is more applicable than the principle of justice, because both would result in the same actions. After presenting the methodology and data of this study, a virtue ethics lens will be applied to the results as a defensible way to empower widows and widowers to revisit or complete advance directive documents, and verify they reflect their current values.

Chapter 3: Methods

This study was classified as exempt human subject research by the Emory Institutional Review Board (IRB). No identifying information was collected from any research participant. All audio recordings of the interviews were destroyed following transcription. An information sheet was provided to all potential study participants prior to beginning the interview. This information sheet was approved by the Emory IRB. All information listed on that approved document was read aloud to potential interviewees by the principal investigator (Kora Dreffs). Prior to beginning the interview, interviewees were asked if they had questions, or if any parts of the information sheet were unclear. Participants were allowed to keep the information sheet for their records. In this way, no written identifying information about the research subjects were collected. Eight persons demonstrated interest in the interview and listened to the information sheet read. Of those persons, one did not want to participate, two agreed to participate as beta interviewees, and five agreed to participate in research collection.

Study Location

This project was a small-scale patient interview project. It was completed at a nursing home in Atlanta, Georgia. This nursing home is part of Emory Healthcare, meaning that no further research proposal was necessary aside from Emory IRB. This facility includes both short-term and long-term patients. There were no specific demographic or socioeconomic background affiliations sought out for this study, making residents at this nursing home an acceptable patient pool for this research.

Study Recruitment

The nursing home volunteer coordinator helped with patient recruitment. Her role allows her to have daily interaction with residents during activities. The volunteer coordinator was provided recruitment flyers which were designed by the primary investigator and approved by the Emory IRB. A recruitment flyer is provided in Appendix A. The volunteer coordinator made the flyer with information about the study to patients who met the inclusion criteria. This was a convenience sample, as flyers were primarily distributed to residents who attended planned activity events by the volunteer coordinator.

If residents told the volunteer coordinator they would be interested in participating, the volunteer coordinator would set up a time for the resident to meet with the primary investigator. The volunteer coordinator alerted the primary investigator of the interested patient, as well as a time when the patient would be available to meet. The primary investigator would take a flyer as well as the information sheet to the resident's room to speak with them and answer any questions they might have. If residents were still interested in the study, the primary investigator would set up a time to return to complete the interview.

Inclusion Criteria

Adult residents of male or female sex from the nursing home were eligible to participate. Participants must have experienced the death of a spouse. Residents could have, but were not required to have, an advance directive document to participate in this study.

Exclusion Criteria

Patients were excluded from the study if they had cognitive impairment (as determined by physicians) or were non-English speaking.

Interview Development

All interview questions were developed by the primary investigator, with feedback and editing tips provided by committee members. Questions were designed specifically to meet the needs of this study. Interview questions were not pulled from any other resources.

Data Collection

All data collection took place in August of 2019. After residents indicated they would like to participate in the interview, the primary investigator set a time with them to ask the questions. All questions were asked in a private room. If patients did not reside in a private room, a private meeting room in the nursing home was utilized. Prior to beginning the interview, the primary investigator read aloud everything on the information sheet. Patients were provided time to ask any questions they had or voice any concerns before beginning the interview. Patients were then alerted when the primary investigator started an audio recording of the interview questions. The interviewees were free to respond with anything they wished to say about each of the questions asked of them.

There were two beta interviews completed, and interviewees were asked to provide feedback on the interview. After the interview was completed, the primary investigator asked participants how the interview process could be improved. These interviews were audio recorded to ensure clarity of sound. After the primary investigator listened to the audio records of the two beta interviews in full to confirm the recordings were clear, the files were destroyed. No answers provided by the beta testers were included for any data analysis in this study.

Five other persons agreed to enroll in the study for data collection and analysis. Again, the primary investigator read the information sheet aloud, and asked if there were any questions or concerns. After addressing questions (if any), the primary investigator alerted patients that a recording had been started. All patients were asked the interview questions provided in Appendix B. When recordings were transcribed by the primary investigator, interviews were coded with a number. No patient names were used. After voice recordings were transcribed, the audio was destroyed. Strict patient confidentiality was maintained, and all electronic data was kept on Emory's password protected system.

Interview Questions

All interviews began with the primary investigator notifying the participant that the recording had been started, then reading the following excerpt: an advance directive is a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure these wishes are carried out should the person be unable to communicate them to a doctor. See Appendix B for a full list of interview questions.

Patient Safeguarding

Participant confidentiality was the highest concern. Interviews were coded with an interview number, and no information was recorded such that any interview could be tied back to a specific participant. All interviews were discussed by a study number, not a name. When the audio records were transcribed, the study number was used. The original audio recording was destroyed after transcription. In-person interviews were conducted in a private room. All electronic data was kept on Emory's password protected system.

Participants were ensured that their completion of the interview was completely voluntary, and that no private health information would be intentionally collected. Interviewees were notified that following transcription of the interview the audio recordings would be destroyed. This study took every occasion to protect participant rights. The interview took place in a private location, participants were not forced to answer questions that they do not want to, and the participants were aware that the interview could be stopped at any point in the process without repercussion.

Data Analysis

Data was analyzed in two ways. First, for the interview questions resulting in numerical answers, a table was made with a simple mean calculation as well as a standard deviation calculation (in years). This allowed for some of the participant characteristics to be displayed for review prior to analyzing the qualitative data.

A simple thematic analysis was performed for the qualitative data derived from the interview questions. Thematic analysis is a flexible method, which allows for identification of themes and patterns found in qualitative data [57]. Previous literature suggests that 6-10 participants are recommended for a small interview project, which is in line with the scope of this study [58]. Step-by-step guides for thematic analysis published in peer-review journals were followed to perform analysis [57, 59]. This approach was adopted because of its popularity among the research community, and flexibility for analyzing various data [57, 60]. Both guides propose the same mechanism with which to analyze data, and follow six basic steps. Those steps are becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes, then writing up results [57, 59]. The principal investigator as well as all thesis committee members deliberated emerging themes in order to confirm results.

Chapter 4: Results

In August of 2019, eight persons demonstrated interest in participating in this survey about advance directives. Of those persons, two acted as beta testers. Both beta respondents said that the interview questions were clear, so no changes were made to the study process or interview questions following the initial round of testing. Answers given by the beta testers were recorded but were not used as viable data for analysis. Six other persons listened to the information sheet, and five of those persons agreed to participate in this study. Of those five participants, four said that they had any form of advance directive document at the beginning of the interview. In all four cases, the advance directive document had been created before the death of the spouse. There were zero participants in this study that had no advance directive documents at the time of spousal death but completed one for the first time following that event.

Of the four participants that had an advance directive document, all reported to have completed an initial advance directives document in or before the year 1992. Using year estimates provided by the interviewees, approximate average time since initial completion was 53.7 years ago. The five interviewees were married to their partners for between 23 and 58 years, with a mean marriage length of 40.2 years. The interviewees reported that their spouses were between 58 and 80 years old at their time of death, with an average age of 72.4 years. All five participants reported at least nine years had passed since their spouse died, with the greatest length since time of death being 48 years. The mean time passed since spousal death for participants in this study was 22.2 years. These results will be examined further in the discussion section. Due to the timing of when advance directive documents were created, this data reveals that participants may have been unclear as to the difference between a financial will and a living will.

Table 1: Advance Directive Interviewee Data

Characteristics	**Interviewee Answers (Years)**	**Mean (Years) ± Standard Deviation (Years)**
Time Since Initial AD Completion	27, 49, 69, 70	53.75 ± 17.6
Length of Marriage	34, 23, 50, 58, 36	40.2 ± 12.4
Spousal Age at Death	79, 58, 67, 78, 80	72.4 ± 8.6
Time Since Spousal Death	19, 48, 16, 19, 9	22.2 ± 13.4

Participant 1

Only one participant, participant 1, reported never completing an advance directive document, and not currently having one. When asked why the participant had never completed a document, the response was “I didn’t really decide it; I just kind of let it sneak up on me.” The interviewee stated that their spouse died of “colon cancer” and that “it was just diagnosed suddenly. Nothing had pointed to such a thing.” A sudden spousal illness and death may help to explain why the person, nor their spouse, had completed any advance directives documents prior to the fatality. However, when asked if the participant had any thoughts regarding no completion of the document, they stated that “I’m wishing right now that I had done it”, referring to completing the document. The participant repeated this sentiment again, claiming that “I just wish I had.” In this instance, the interviewee did not shed any further light as to why an advance directive document had not been created following the death of the spouse despite them wishing that they had one. While there was only one participant in this small interview study that did not currently have any form of advance directive document, the responses given to the questions may imply that this idea should be a topic of return conversation with the patient.

<u>Participant 2</u>

Participant 2 did have an advance directive prior to their spouse's death. When asked why the document was completed, the participant responded that they wished "that my family would be taken care of." The interviewee did not elaborate as to whether they meant they did not want their family members to have to sort through end-of-life decisions, or how the document would allow their family to be taken care of. This participant did not recall telling anyone when initially completing the document, but said they, "may have told my sister or my mother." When asked who helped initially complete the document, they stated "I think my spouse and I did it with an attorney, but I'm not sure." The interviewee also claimed to have no reason, "not that I can remember" when asked if there was a specific reason the document was initially filled out. They also said they do "not really" remember asking any specific questions when they filled the document out. After the initial document was completed, the participant said they stored it "in my safety deposit box but I don't know who would get to it other than my husband." In other words, there were no other persons provided copies of the advance directive document in the case of participant 2. Participant 2 did not make any memorable changes regarding health care to their advance directive document following the death of their spouse. According to the interviewee, their spouse died of "a heart condition…chronic." They said that, "I may have reviewed it when my husband passed away and changed it at that time…and left everything to my daughter." Again, this statement makes it unclear if the participant knows what is contained in an advance directive document. They proceeded to say that "I think she [the daughter] will take care of things." It was not further elaborated on what decisions the participant thought the daughter would be making in the future.

Participant 3

The third participant had an advance directive prior to their spouse's death. However, they said "no" when asked if they had revised the document following the death of their spouse. As stated by the interviewee, their spouse died "cutting grass for the neighbor, and slid off the riding lawnmower, and it turned over and broke his neck." When asked if the document was revised following the death of their spouse, the participant responded that "we had already gone over it." The participant did say that since that time, "I've read it." But did not mention any changes made. They claimed that they initially filled out the advance directive document "so the children would know." At the time, the participant stated that "a lawyer" was the only one present when completing the document. They thought that they "just filled it out and signed it" without asking any questions regarding the decisions they were making. At the time of initial completion, the participant said that "our son was killed, and that might have made us" fill out the document. They did not tell anyone of the document besides "the lawyer and the children." The interviewee said that they kept a copy "in the safety deposit box" and when asked if anyone else had copies, they answered "no." When asked whether or not the participant had any final thoughts regarding advance directives, they said that "I think it is good for family to know." This participant did not mention any particular parts of the document that were important for other family members to know about.

Participant 4

Participant 4 said that “my husband and I both did one” when asked if they had completed an advance directive document. They said that, at the time of initial completion, there was “not really” a reason they did so. When that document was completed, they sought out “a lawyer.” The participant made clear that they had special considerations in mind when completing the document since they “had an adopted child.” Also, the interviewee mentioned that the wishes most important to them were “cremation” and stated that “I still have not firmly decided” if they want to be cremated or not. Another important consideration they mentioned was that they “do not want resuscitation” and that “if I am to that level, then my son has all kinds of authority.” When asked who received copies of the document, the participant answered, “the lawyer [and] my son.” The participant claimed that they have “turned everything in my safety deposit box over to my son.” When asked about their spouse’s death, the interviewee stated that “he had Alzheimer’s. The last five years that he lived I took care of him at home. I would not put him in an institution. It was rough.” The participant then answered that they reviewed their document “after my husband passed away.” They stated that “there were two little revisions…it was a change to the children. But, after [daughter’s name removed for privacy] death, then I did it again. We went to an attorney after my daughter passed away last year. So that changed a lot of things. I had to have a new will written.” The interviewee did not make any specific remarks regarding a change in health care planning. When asked if there were any additional comments, the participant said that “while I am of sound mind, I wanted to take care of it.” They proceeded to say that “I think it is ridiculous not to face the facts.” The interviewee further expanded on their thoughts by saying “I think everybody should do it. Absolutely. My mother and father had it all in place. It was in place when my husband died. And it will be in place when I die.” Of note is that the participant found the document to be very important and stated that the last remaining years with their husband was rough. Yet, there still remains indecision on some end-of-life choices, as well as making no mention of concrete health care changes following the death of their spouse.

Participant 5

Participant 5 felt very strongly about advance directive completion and provided many insights during their interview. This participant answered "yes" to whether or not they had an advance directive document. When asked who was present when completing the initial document, they said "my spouse and I discussed it, so we kind of already knew. And then we had the lawyer draw up all the papers. So, she was the other person who inputted." The interviewer then asked if there were any specific questions about the document discussed at that time, and they said "with the lawyer? Not really. I can't remember to tell you the truth." They said that the reason for initial completion was that "we were just getting the legal paperwork together for our daughter." The participant also stated that the documents were completed "to take the burden off of each other in case there was a tragedy of any kind or if one of use needed it." The participant was referring to any burden that might result from a tragedy impacting them or their spouse. The interviewer asked if anything particular was important to be recorded when first completing the document. The interviewee answered that "I think that the main thing, and this is paraphrasing, is that we wanted it made clear that if we were in a vegetative state that no extreme measures would be taken. That was the main thing. Also, like you said, to make sure all the decisions were there in case I couldn't answer for myself, and he did the same." When asked if they told anyone about the initial completion, the interviewee responded that they talked to "nobody really. He and I just did it." The next question asked who received copies of the document, and the participant stated that “the lawyer kept it and was to act on our behalf if both of us were not around.” In addition, they said that copies were stored in “a safety deposit box. And I have extra copies sitting around the house.” The participant stated that they had made multiple revisions to their document. They said that “the first one I can remember is ’92. Then, there was another one probably around 2000, and then there’s another one in 2013. The 2013 one is current. By that time my husband was gone, and I changed all of the paperwork and went to a different lawyer. Have a new will essentially as well. I did all of that at the same time.” The interviewer then asked how their spouse died, and the interviewee stated that

> He had Parkinson’s. And he had a stroke… I think that, in part, he chose to die by stopping eating. As I said, he had a philosophy that he wanted to have a choice. He had just become unable to walk, and that was a huge blow. I think he just decided that his quality of life was going to be such that he was going to stop eating. It is true that he had a stroke. That led him to not be able to use his leg, and therefore he couldn’t walk. It is true that sometimes if you have a stroke you have more. But I know from sitting with him in the hospital for the two weeks before he passed, or three weeks, he wasn’t eating. He was drinking a little water, but he wouldn’t eat. So, yeah, that’s what I think. I think he decided that his quality of life was such that he was ready to not be here.

The interviewer then asked if the advance directive document was updated following the death of the spouse. The participant responded “not really following his death… I think by that time we were using a standard form anyway. So, there really wasn’t any need. I think a lot of lawyers have a standard form to ask people what they think, and they say yes or no, and then off they go.” Finally, the participant was asked if they had any closing remarks they would like to add to the conversation about advance directives. One comment they made was that “especially for people who are hospitalized, they should do something to make sure that it is there, and they have one and they honor it. That is a big important thing to me.” Also, the participant noted that

> I guess when I first started thinking about this, didn’t really understand what it was. I think that education would help people and make people more aware of it. To explain what’s going on, and how your answers will affect what happens in reality. I think that would be helpful, because that was what I needed. And I realized that the last time I signed one that I had confusion in my head about one of the things, and we finally got it clarified. I think that terms are thrown around, and that is about all I can say.

The participant did not provide any further feedback regarding their thoughts on advance directives.

Thematic Analysis

Each interviewee provided a different perspective on advance directives, and what was most important to them. One out of five participants did not have an advance directive document, but demonstrated they wished they would have completed one. After reviewing the data, three major themes emerged from the feedback provided by participants 2-5, who had completed a document. Those three themes included a lawyer being involved in completing the advance directive document, general confusion about what an advance directive document is, and not revising their documents following the loss of a spouse.

All four participants with an advance directive document said they talked to a lawyer or attorney when filling the document out. Participant 2 was not sure, but thought an attorney was consulted. Participants 3, 4, and 5 all specifically noted that they completed the document with a lawyer present. None of the participants mentioned particular questions that were asked of the legal consult when filling out the document. However, educating legal personnel on advance directive documents may prove to be beneficial, and will be returned to in the future directions section.

Another theme seen in the interviews was confusion regarding a living will and a financial will. Participant 2 made a reference that seems to be about money, when saying that they left everything to their daughter. This seems to imply they are talking about a financial will, and not a living will. Participant 3 was vague in responses, and just said it was important for their children to know about things. It was unclear as to whether that meant their end-of-life wishes, or other items covered in a financial will. Participant 4 discussed cremation and a do not resuscitate order at the beginning of the interview but did not refer to items related to a living will as the interview continued. Additionally, they mentioned that after death the changes made were related to the children. This seems that no healthcare items were changed, but rather changes were made to their financial will following the death of the spouse, and then again after the death of their daughter. Participant 5 was the only interviewee that made it clear via their responses that they were aware what a living will covers, and the differences between that and a financial will. The participant even mentioned a need for education, as they themselves had been concerned about some of the terms when first completing the document.

A third theme to be noted is that none of the four participants with advance directives could articulate any specific end-of-life healthcare concerns that caused them to update their document following the death of a spouse. Participant 2 claimed they thought their daughter would take care of things but did not provide specific details as to health considerations they would be interested in their daughter having a plan for. Participant 3 noted that they had already gone over the document prior to the death of their spouse. It is unclear whether or not they might have differing opinions as time progressed that might cause them to update their advance directive. Participant 4 noted how rough it was taking care of their spouse with Alzheimer's at the end of his life, yet they did not note that these experiences caused them to update their advance directive document. With the emotional salience surrounding the last years of their spouse's life, it may be possible that the interviewee should revisit their advance directive document to ensure that it accurately represents their current values. Participant 5 stated that they have made various revisions to both their advance directives document and their financial will. However, this was not triggered by the death of their spouse. Reviewing advance directives regularly will be beneficial to verify values are accurately documented. A virtue ethics approach would support a reviewing advance directive documents regularly. This idea will be returned to in the discussion, where a virtue ethics lens will be applied to all five of the participants in this study.

Table 2: Quotes Associated with Thematic Analysis Takeaways

Theme	**Participant Quotes**
Persons Consulted While Completing Advance Directive Document	"I think my spouse and I did it with an attorney, but I'm not sure." – Participant 2 "A lawyer." – Participant 3 "A lawyer." – Participant 4 "We had the lawyer draw up all the papers…she was the other person who inputted." – Participant 5

Confusion Regarding Living Will vs. Financial Will	"At that time, I may have changed it, and left everything to my daughter." – Participant 2 "Well I just think it is good for the family to know." – Participant 3 "Well it was a change to the children. I have a son by natural birth and the daughter by adoption." –Participant 4 "Yes. Actually, the first one I can remember is '92. Then, there was another one probably around 2000, and then there's another one in 2013. The 2013 one is current. By that time my husband was gone, and I changed all of the paperwork and went to a different lawyer. Have a new will essentially as well. I did all of that at the same time." – Participant 5
Medical Revisions Following the Death of a Spouse	"No, I think she [the daughter] will take care of things." – Participant 2 "Well, we had already gone over it." – Participant 3 "Well, after my husband passed away. There were two little revisions…it was a change to the children." – Participant 4

	"No. I think by that time we were using a standard form anyway. So, there really wasn't any need. I think a lot of lawyers have a standard form to ask people what they think, and they say yes or no, and then off they go." – Participant 5

Chapter 5: Discussion

This final chapter will be dedicated to establishing how virtue ethics can provide meaningful guidance and motivation for the recently bereaved to attend to pressing end-of-life care decisions. To begin, this chapter will apply a virtue ethics lens to the data obtained in this study in order to speculate on how best to empower bereaved spouses to verify that an advance directive document, or lack thereof, reflects their current values. Next, this chapter will detail the limitations of this study, as well as provide ideas for future directions this work may take. Finally, this chapter will assess three industries that could help operationalize the reexamination of bereaved persons' advance directive documents following the death of their spouse.

Results Discussion

This small pilot study included two beta interviewees, followed by five interviews recorded for data analysis. All participants were residing in a nursing home in Georgia, which requires certain stipulations about advance directives are met according to the patient self-determination act. Those five mandates are:

1. Provide written information to patients concerning their right under state law to make decisions about their medical care and the right to formulate advance directives.
2. Maintain written policies and procedures regarding advance directives and make them available to patients upon request.
3. Document whether or not the patient has executed an advance directive.
4. Comply with the requirements of state law respecting advance directives.
5. Educate staff and community on advance directives. [5].

This may have increased the likelihood that participants had advance directives documents in place at the time of the interview, and may be the reason why four out of five interviewees had advance directive documents. However, this question was not asked of participants, and may be added in future studies to address this speculation. One participant did not have an advance directive when their spouse died and stated that they still did not have any advance directive document. In the responses, three main themes were revealed:

- A lawyer being involved in the advance directive preparation.
- Confusion over the purpose of an advance directive.
- Not revisiting advance directive documents following the death of a spouse.

The information collected in this study included time since initial advance directive documents were completed (mean of 53.75 years ago), length of marriage (mean of 40.2 years), spousal age at death (mean of 72.4 years), and time since spousal death (mean of 22.2 years ago). First, since initial advance directive documents were completed by participants (on average) more than 50 years ago, it is clear that at least some of the interviewees did not, or do not, know what these documents are. This is because the first living will document was not recognized until 44 years ago, which means that it was impossible for interviewees to have completed their initial document 50 or more years ago. The length of marriage was approximately 40 years across all study participants. With the limited number of participants, no conclusions can be drawn as to whether or not marriage length impacted no change to advance directive documents seen among the bereaved spouses. Lastly, spousal age at death was a mean of approximately 72 years old. The older persons are, the more likely they are to have completed an advance directive document [21]. This meant there was a higher chance for those who participated in this study to currently have an advance directive.

Primary Themes Discussion

All four of the participants with a completed advance directive document stated that they filled their initial document out with a lawyer/attorney. This aligns with previous studies, which indicate that persons consulting with lawyers are more likely to have an advance directive than persons who have not [12, 24]. Specifically, in this study, three persons said they had a lawyer present when initially filling out an advance directive document. A fourth participant thought they completed their advance directive document with an attorney. Of note here is that lawyers were commonly sought out, yet were not asked any questions about the documents by the study participants. No interviewees elaborated on why they did not ask their lawyers questions about their advance directive documents. So, it was unclear if persons had questions about the documents but were afraid to ask, if they already had their minds made up and did not need to consult their legal counsel with questions, if the participants could not recall the meeting in detail, or if the lawyers did not ask if there were questions/felt unable to answer questions.

The second major theme was a general confusion about what an advance directive document, specifically a living will, is when compared to other documents like a financial will. Only one of the four participants with an advance directive made it clear in their responses that they knew what the difference was between a living will and a financial will. This is important to note, as at the beginning of the study the principal investigator read the definition of an advance directive document. The three participants who seemed to be unclear as to the difference between the documents made comments like “left everything to my daughter” (Participant 2) when asked if they had ever updated or revised their advance directive. Participants 3 and 4 provided vague responses, saying that the documents they initially completed were “good for the family to know,” and “it was a change to the children,” respectively. Neither made specific comments indicating what an advance directive document was used for in their case. Participants

2, 3, and 4 were the interviewees that answered they completed their advance directive documents 49, 69, and 70 years ago. Since advance directive documents were not yet proposed 69 or 70 years ago, nor 49 years ago in Georgia, there is additional skepticism that these participants knew the difference between a living and financial will. This general confusion might have resulted from participants not understanding which document the interview questions were asking about. The limitation section will further flag this confusion, as well as provide recommendations to obtain more specific answers from interviewees.

The third major theme seen was no revisions made to end-of-life care preferences in advance directive documents following the death of a spouse. While participants did note some changes to those documents, they did not specifically address healthcare preferences. Participant 4 said, “it was a change to the children.” This comment does not address end-of-life care preferences. Rather, one possible conjecture is that this interviewee was implying that their financial will was revised to reflect that they wanted their assets to go to their children. There was no further commentary provided on this by the participant. Participant 2 stated that “she [the daughter] will take care of things.” However, the participant did not note if the things to which they were referring were healthcare decisions. Participants 3 and 5 mentioned that “we had already gone over it” and “we were using a standard form…so there really wasn’t any need,” respectively. Again, these responses do not demonstrate any changes to advance directive documents following the death of their spouse. Taken together, none of the participants with advance directive documents specifically mentioned changes to end-of-life care preferences being updated following the death of their spouse. This does not mean that revisiting advance directive documents should be overlooked. Even if these persons are confident in their choices, there is no harm in reminding them of the importance of reassessing advance directive documents. For other persons that are not confident in their choices, a recommendation to reconsider their advance directive is a defensible way to help verify that their preferences reflect their values.

Ethical Discussion

While no persons completed or updated their advance directives after the death of a loved one in this study, it is still beneficial to note how virtue ethics can be applied here. Virtue ethics provides a means by which persons can determine their values and priorities. With those values in mind, persons should then verify that an advance directive document, or lack thereof, effectively articulates their ideals. This discussion will look at the responses of each participant, and use virtue ethics as a justification to embolden bereaved spouses to complete a new advance directive document or revisit an existing document. Additionally, some speculation will be provided on how best to empower these individuals to meet those goals.

Participant 1 stated that they did not have an advance directive document before their spouse died, and still do not have one. This participant repeatedly specified a desire to complete an advance directive document, but could not explain what was holding them back from completing one. In this scenario, it seems to the author that the participant was unaware as to the steps that would need to be taken to complete an advance directive document. This conclusion stems from the fact that the participant wanted to have their wishes documented, but could not say what was keeping them from competing an advance directive. To help this individual meet their goal, they could be provided with a Georgia advance directive document to complete. In this way, they could document their wishes for end-of-life care.

Participant 2 did not mention any healthcare changes to their advance directive document following the death of their spouse. Of note, however, was the mention that everything was to be left to their daughter. One possible rationale is that the interviewee was confused about what a living will is, and how it differs from a financial will. To better empower this participant, further clarification should have been sought out on their understanding of advance directives. If they currently had an advance directive document which listed their values but chose not to make changes, that would be acceptable. However, this interviewee should confirm that their preferences are up to date.

Participant 3 provided short, vague responses related to advance directives. They made no mention of any end-of-life care preferences. However, the participant answered that they did not make any revisions to their document because they had already gone over it. In this way, it is possible that this interviewee was confident in the decisions they previously made regarding their end-of-life care. Virtue ethics does not mandate that a change has to be made to an advance directive document. But, it is important to revisit these documents to confirm that the document accurately reflects the values of the person whom it represents. For this participant, the best way to empower them is to confirm that their wishes are accurately documented via a reexamination.

Participant 4 began the interview by specifically noting their preferences on do not resuscitate measures, as well as current indecision on cremation. This initially made clear that they were discussing healthcare preferences related to the end of life. However, after noting that their spouse died following a battle with Alzheimer's, the participant stated that a change made to documents was a change to the children. This makes it unclear as to whether the participant was still referring to a living will, or if they were then thinking of a financial will. The interviewee offered up no further information as to the changes made, or why they were made. The material shared with the author about the interviewee's spouse dying after a difficult battle with Alzheimer's was especially salient. One possible conjecture based off of this information is that the interviewee may no longer want extreme measures to be taken at the end of their life to limit the possibility they also have to live with diminishing memory. To empower this person, it would be advantageous to encourage them to revisit their advance directive. Even if this person still prefers extreme measures be taken at the end of their life, it is important to verify this document accurately reflects their current values.

Participant 5 provides an example of the ideal role that a virtue ethics framework can play in advance directives. The interviewee mentioned multiple occasions on which they reviewed their advance directive. As they aged, and the values most important to them changed, they reviewed their advance directive multiple times. While they did not make any changes following the death of their spouse, they still had previously reviewed it and made updates. By taking seriously the importance of revisiting their advance directives, this interviewee had confidence that their end-of-life care plan reflected their values. Therefore, this person did not feel the need to review their advance directive following the death of their spouse. Admittedly, this seems like an ideal scenario -- a patient revisiting their advance directives without outside prompting. However, not all persons will take this initiative. To empower everyone to revisit their advance directive documents, three possible pathways will be flagged in the future directions section which will help to operationalize this procedure.

Limitations

This interview sought to extrapolate novel information about advance directive changes or initial completions following the death of a spouse. There were some limitations to the interview process, and three methodology limitations will be detailed for future considerations.

One limitation of this study was the lengthy average time between interview completion, and spousal death. This may have impacted the memory of the bereaved, and the specific events that happened during the end of their spouse's life. For example, one interview question asked for specific reasons why persons did not make changes to their advance directive following the death of their spouse. For interviewees that lost their spouse decades ago, one possibility for a vague answer is that they may not recall why no changes were made. In future studies, questions may be tweaked when interviewing persons that lost their spouse many years ago which do not focus as much on details, but more so on the underlying values that may be at play when developing or revisiting advance directive documents.

A second limitation was the curtailed nature of the responses that interviewees provided to the questions asked of them. In the future, interview questions related to this topic should be prepared with the intent of gaining more thorough information. One such question to gain information may be whether or not the notice regarding advance directives given to patients upon entrance into the nursing home motivated them to complete or review their advance directive document. Further, more probing questions may have helped make clear whether or not participants fully understood the difference between an advance directive and financial will. While these interviews began with the investigator reading a definition of what advance directives are, future work should be even more clear. For the participants that stated they initially completed their documents 49, 69, and 70 years ago, it may have been beneficial to ask them what kind of information they believe can be found in a living will. By eliciting this information, there would be a chance to correct misunderstandings. With a better understanding of what was being discussed, the interviewees may have provided different answers.

A final limitation of this study was the small sample size. While this project was undertaken with the knowledge it would be a small pilot study, future studies should seek out more study participants. By including more participants, it may be possible to find persons that updated their advance directive documents following the death of their spouse. If there are participants who meet that criteria, it may be beneficial to study how one responds to altered contexts (like the loss of a spouse) or how one maintains a commitment to their previous values despite a change in circumstance. With more knowledge of events that may lead to updating or completing these documents, other avenues than the three presented in the future directions section may be unveiled as a means to help engage persons in a reexamination of their advance directives. Additional work may help to strengthen the idea that virtue ethics plays a role in revisiting advance directives following circumstances other than the death of a spouse.

Future Directions

This small, interview-based project was a first step for an interesting area of further research. This was a novel study, which helped reveal that the best way to uphold a virtue ethics framework for bereaved spouses is to empower them to reexamine, or initially complete, their advance directives. With this in mind, three industries will now be discussed that can help persons reconsider their end-of-life care plans. It is important to note that all three avenues have both strengths and weaknesses, but all are able to provide meaningful interactions with this population. Future focus ought to be on the virtues of the bereaved, and verifying that their advance directive documents reflect their current values.

Hospice Bereavement Care

The first future direction this thesis aims to highlight is working closely with bereavement care specialists, specifically those working for hospice. Medicare benefits stipulates that “bereavement counseling is a required hospice service, provided for a period up to 1 year following the patients’ death” [61]. This type of counseling is defined as “emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment” [62]. This care is required by law, but there are no specific requirements as to how hospice providers meet those criteria. Since there are no governmental requirements as to the exact type or amount of care provided, this can impact the “breadth and magnitude of services offered” [63].

One study, published in 2015, claims that hospice bereavement care is missing the mark [64]. While bereaved caregivers felt that hospice provided adequate care helping their loved one transition at the end of their life, they often felt that “hospice staff did not do much to facilitate their own bereavement needs” [64]. This is because the phone calls and letters sent to the bereaved were “interpreted…as somewhat impersonal and generic” [64]. As some participants in the study implied, “these forms of contact were typically not enough to draw caregivers to use the services” [64]. One specifically mentioned area that was lacking was “not having conversations about end-of-life preferences and wishes [which] can lead to rumination about whether the caregiver did everything possible for the dying spouse” [64].

While hospice may currently be missing the mark in providing bereavement care, it is not to say that hospice bereavement care is a complete failure. As noted in the study, bereaved spouses specifically mention that they want to have conversations about end-of-life care. This identified need provides a gap which could be filled. To begin with, there should be more regulation as to what kind of hospice bereavement care is required. Secondly, there should be a greater focus on more personal and individualized communication. This tailored contact may make persons feel more comfortable discussing personal values and virtues with hospice contacts. Personalized contact may enable a sense of hope, as the bereaved feel they have persons who are genuinely interested in their grieving process. Additionally, this sense of connection may help widows and widowers feel more courageous, by establishing ties with others they can come to rely on in the future. This will help the bereaved to cultivate some of the virtues that have been flagged in this thesis as important. To empower the bereaved, hospice should be required by law to have more meaningful interactions with this population beyond a universal letter or phone call. In this way, hospice bereavement programs may help ensure that advance directive documents, or lack thereof, reflect the current values of the bereaved spouse.

Lawyers

Another route for further research is requiring that lawyers are educated on advance directives in their state, and compelling them to have discussions with their clients about these documents. The American Bar Association has a free counseling guide to help assist lawyers with completing client advance directive documents [65]. Additionally, this counseling guide encourages lawyers to recommend that their clients revisit their advance directive documents whenever they experience one of the “six D’s” in life [65]. Those instances include a new decade in age, death of a loved one, divorce, diagnosis of a significant health condition, significant decline in functional condition, or changing domicile [65]. However, this document being available online does not necessarily mean that it is utilized by lawyers, or put into practice.

This thesis added to current data which has found that persons seek out legal counsel when filling out advance directive documents. Various study participants mentioned changes that were seemingly made to their financial will following the death of their spouse. While this study was not specifically interested in that information, it was noted by multiple study participants. When persons update their financial will documents with an attorney following the loss of a spouse, this may be a time to engage the clients in whether or not they wish to revisit or complete an advance directive document. These conversations may help the bereaved develop the virtue of fortitude. In turn, this increased cultivation of fortitude may help the bereaved maintain strength of mind to move forward despite the death of a loved one. Currently, the death of a loved one is recommended by the American Bar Association as a time to encourage clients to revisit advance directive documents. However, this is not required. If this scenario has been recognized by the American Bar Association as a salient moment which may require revisiting these documents, then their current recommendation should be heightened to a more formal requirement. Even if clients signed their initial advance directive document decades ago, lawyers should take seriously the importance of persons revisiting their advance directive documents. These clients may say they wish to make no changes, or do not want an advance directive document at all, but lawyers should embolden the bereaved to create a document which reflects their current values.

Funeral Homes

A final direction for future work is funeral homes. Initially, this recommendation may seem unsuitable. Funeral homes can be thought of as lucrative businesses with transactional interactions. However, funeral homes may be incentivized to empower the recently bereaved by encouraging the completion of an advance directive document like Five Wishes, which includes a section where persons can clearly list their final arrangement plans [66]. If persons complete living wills which document their final arrangement plans, their values can be respected postmortem. Additionally, funeral homes can be reasonably expected to provide advance directive documents for the bereaved. In 2012 alone, these funeral homes accounted for $16,323 million in profits [67]. This is not surprising, as the national median cost of a funeral (including viewing and burial) is $7,360 dollars [67]. As per the fivewishes.org website, purchasing 25 copies or more of the Five Wishes document costs only $1/copy. Therefore, these funeral homes can afford to purchase and disseminate copies of this living will document.

This thesis will concede that some funeral homes may treat this as a lucrative deal. This will allow them to maintain ties to the bereaved and form a relationship with them, leading persons to use their services in the future, or recommend their services to others. But, the focus of this thesis is to propose avenues to empower bereaved spouses. If these persons have access to a copy of a living will, they can create a new document or be reminded to revisit an existing document to make sure it accurately reflects their current values. Additionally, this may help cultivate prudence in bereaved spouses. Providing these documents may help the bereaved exercise good judgment in reviewing, updating, or initially completing an advance directive. Even if these persons were confident in their earlier decision-making, providing them with a living will is an easy way to encourage them to reexamine their beliefs, and verify that their advance directives are up to date. While making a miniscule financial outlay, funeral homes will both educate persons as to decisions available to them to create an end-of-life road map, as well as empower them on their virtues.

Conclusion

This study was a starting point for further research on updating or completing advance directive documents following the death of a spouse. It sought to fill a gap in current research by directly interviewing persons who had lost a spouse, and asking if that event sparked changes in advance directive documents. Among the interviewees in this study, there was confusion as to the differences between a living will and a financial will. Future studies would do well to verify that participants are clear on the differences between living wills and financial wills by asking further probing questions. Following the finding that no interviewees updated or completed an advance directive document after the death of a spouse, this thesis shifted its aim towards means to empower the bereaved. In this way, the new goal of the thesis was to apply a virtue ethics lens to make sure that advance directive documents were representative of the values held by the bereaved.

This thesis maintained the premise that virtue ethics is a better alternative to addressing end-of-life decisions than utilitarianism, deontology, or principlism. Virtue ethics allows for a focus on bereaved individuals, and provides room for changes in value. That is where utilitarianism and deontology fall short. When compared to the principle of autonomy, virtue ethics permits more trust in the bereaved to make end-of-life decisions that are in line with their values. This is because virtue ethics holds that persons who have cultivated meritorious virtues their whole life will be able to make decisions that allow them to flourish. Autonomy, however, has stipulations which may result in an inability for the bereaved to make autonomous decisions. The principles of nonmaleficence and beneficence are relevant to end-of-life care, but are more applicable to caregivers than to the bereaved persons themselves. Therefore, virtue ethics better meets the goal of focusing on empowering the bereaved. Lastly, justice is both a principle and a virtue, so no argument was made as to whether justice as a principle or justice as a virtue is superior to the other. These considerations helped to bolster virtue ethics as a suitable framework to approach advance directives and end-of-life planning for bereaved spouses.

There is a current lack of studies exploring the relationship between virtue ethics and end-of-life care, which is a major setback. This study highlighted four specific virtues for the bereaved to tackle end-of-life care planning – courage, fortitude, prudence, and hope. These virtues were chosen because of the potential for them to be elicited by three various proposed pathways. When the bereaved are empowered to make sure their advance directive documents are in line with their values, they are able to cultivate courage, fortitude, prudence, and hope.

First, since hospice programs are required by the government to provide bereavement care, it would be a simple addition to add on information about advance directive documents. This extra effort may also allow the bereaved to feel like the hospice programs are more genuine in their communications following the death of their spouse. If hospice programs provide more authentic interactions with bereaved spouses, widows/widowers may better cultivate hope. This feeling may be brought on by recognizing that hospice programs truly care for the bereaved, and do not wish for them to feel alone. Additionally, new connections formed through updated hospice bereavement programs may allow persons to take courage in what the future holds as a new widow or widower.

Secondly, this study revealed that persons often visited an attorney following the death of their spouse. With additional education, lawyers may be able to more effectively meet the needs of their bereaved clients. If conversations are had about advance directive documents, lawyers may help inspire fortitude. They will be promoting strength, and may help the bereaved to take sensible steps forward following the death of a spouse.

Lastly, funeral homes ought to provide advance directive documents to the bereaved. Instead of requiring funeral home ambassadors to discuss advance directives with the bereaved, which may be considered a conflict of interest, these businesses should be required to provide advance directive documents to their customers. This will provide the bereaved a means to complete an advance directive document, or remind them to revisit their existing documents. Funeral homes may help persons cultivate prudence by offering these documents, and potentially catalyzing the bereaved to use those resources to verify that their end-of-life wishes are accurately detailed.

These three avenues were recommended with one goal in mind – to focus on the needs of bereaved spouses, and make sure their advance directive documents reflect their current values. By operationalizing the procedure of reexamining advance directive documents, there will be an increased focus on the virtues of the bereaved. Hospice bereavement programs, lawyers, and funeral homes provide three different avenues to begin meaningful interaction with this population.

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Appendix A

Adapting or Completing Advance Directives Following the Death of a Spouse

Principal Investigator: Kora Dreffs, Emory University, Master's student in Bioethics

Summary: This study will use an interview-based approach to determine whether or not individuals may update their advance directives, or complete one for the first time, following the death of a spouse. Previous studies have shown that advance directive preferences generally stay stable over time. This study seeks to determine whether or not the death of a spouse may have an impact on review or completion of an advance directive. Advance directives are documents that allow persons to detail wishes for their end of life treatment.

The researcher seeks 5 people who would participate in a confidential interview, which is anticipated to take 30 to 45 minutes. The responses will then be analyzed to see what can be learned about how advance directive preferences are affected following the death of a spouse. No information identifying the participant will be included in the analysis.

Interested in Participating? Please contact Elizabeth (email address removed for privacy)

Appendix B

1. Do you currently have an advance directive (AD)?
    a. If yes, proceed to Q2-Q14. If no, proceed to Q15-Q19.

2. When did you complete your first advance directives document?
3. Was there a reason or incident in your life that led to your completing the AD at that time?
4. Who did you speak with when filling out your initial advance directives (spouse, children, lawyer, physician, etc.)?
    a. How did they assist in completing your AD?
    b. What kinds of questions did you discuss?
5. Overall, what decisions or information did you want the AD to address?
    a. What was most important to you in completing the AD?
6. Who did you inform about your AD?
7. Who did you give copies of your AD to and/or where did you place copies?
8. Have you reviewed your AD since completing it?
    a. If yes, how often do you review your AD?
    b. If no, proceed to Q10.
9. Have you ever updated or revised your AD?
    a. If yes, when? At what occasion? How often?
10. How long were you married to your former spouse?
11. How did your former spouse die?
    a. How many years ago? How old was your spouse at their death?

12. Are you willing to share a little bit about the circumstances surrounding your spouse's death?
    a. If yes, did your spouse deal with an illness that contributed to their death?
    b. Was this a chronic illness they dealt with for some time? Or was this an acute illness?
13. Following the death of your spouse, did you change any element of your advance directive?
    a. If no, were there any specific reasons you didn't make any changes?
    b. If yes, what did you change?
    c. Were your revisions related to information and decisions you experienced in your spouse's care and treatment? Would you share a little about that?
14. Is there any other information that you would like to share about decision-making and the use of advance directives? (End of interview for persons that have an AD)

15. Have you ever considered completing an AD in the past?
    a. Was there a reason or incident in your life that led you to consider completing an AD?
    b. Why did you decide not to complete an AD at that time?
16. How long were you married to your former spouse?
17. How did your former spouse die?
    a. How many years ago? How old was your spouse at their death?
18. Are you willing to share a little bit about the circumstances surrounding your spouse's death?

   a. If yes, did your spouse deal with an illness that contributed to their death?
   b. Was this a chronic illness they dealt with for some time? Or was this an acute illness?

19. Is there any other information that you would like to share about decision-making and the use of advance directives? (End of interview for persons without an AD)