

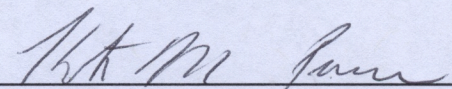
PHYSICIANS' END-OF-LIFE HEALTHCARE DECISION-MAKING

By  
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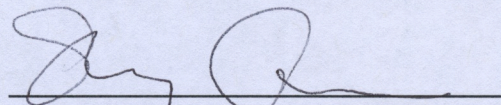
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## ABSTRACT

Through a qualitative approach, this thesis seeks to gain a better understanding of end-of-life healthcare decision-making among physicians as well as among non-physician elderly individuals. I investigate both attitudes and knowledge regarding advance directives, decision-making concerning end-of-life healthcare, and the patient-doctor relationship in order to understand why physicians make relatively more conservative end-of-life healthcare decisions than the general public does. Ten non-physician individuals living in retirement communities primarily in the Chapel Hill/Durham area and ten physicians of different specialties working in this region were interviewed. Using non-physician participants' and physicians' own words, this study explains the different factors important to these two groups in the end-of-life healthcare decision-making process. Results indicate that the current healthcare system regarding end-of-life healthcare defaults to life-prolonging treatments which non-physician individuals are generally ill-informed about and do not want. Physicians' backgrounds and experiences greatly influence their personal decision-making and their ability to successfully navigate the healthcare system. Non-physicians and physicians did not desire heroic measures and the role of families was essential to both groups. These results suggest that non-physician individuals are generally not receiving the end-of-life circumstances they desire due to ineffectiveness of the PSDA and the unsuccessful implementation of advance directives as well as barriers in communication.

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## CHAPTER 1: SIGNIFICANCE

### Introduction

With the passage of *The Patient Self-Determination Act* (PSDA) in 1990, federal law mandated that all hospitals and healthcare institutions inquire about patient's medical advance directive status and inform them of their right to agree to or to refuse medical treatment (Ulrich, 2001). An advance directive in the United States today refers to the power of attorney for health care and to the living will, both of which are legal documents that may be filled out independently by individuals (Ashley, 2005). With this, the PSDA transitioned some responsibilities from healthcare practitioners to patients. It required all healthcare institutions to provide patients with a written summary of their healthcare decision-making rights, as well as with a number of other items. These items included the facility's policies with respect to recognizing advance directives at the time of admission, asking patients if they have an advance directive (and documenting it if so), educating hospital staff and the local community about advance directives, and not discriminating against patients based off of their advance directive status (Ulrich, 2001).

Prior to the passage of the PSDA, in 1989, the Journal of the American Medical Association published a study examining physicians' opinions on the standard arguments for and against advance directives. In this paper, Davidson *et al.* surveyed 790 practicing physicians in Arkansas using a 14 item advance directive (AD) attitudes questionnaire to assess doctors' opinions towards advance directives. Expanding on this, in a study later conducted in 2013 by the Stanford University School of Medicine, Periyakoil *et al* used this same 14 item AD attitudes questionnaire to compare responses of the 790 doctors from the 1989 cohort serving as a control group to a cohort of 1147 doctors from two large academic hospitals (Periyakoil et al., 2014).

Their goal was to “better understand the current attitudes of doctors and to assess for any changes in doctors’ attitudes” towards advance directives since the passage of the PSDA in 1990 (Periyakoil et al., 2014). The conclusion of this study was that physicians’ attitudes had not changed significantly since the passage of the PSDA according to survey questions and responses of questions asked in the AD attitudes questionnaire. These attitudes generally indicated that the majority of physicians surveyed expressed a positive stance in regards to advance directives, and that their experiences in practice had contributed to their positive outlook. Physicians also generally cited improved communication and trust in their relationships with their patients, as well as the promotion of patient autonomy as benefits of using advance directives. These studies brought to the forefront the question of why physicians continue to provide heroic treatments for their patients when they would opt for much more conservative end-of-life healthcare options for themselves. Conservative is used in this sense to refer to opting for less invasive treatments, stopping treatment, and/or avoiding heroic treatments in most cases.

In this study, the same advance directives attitude questionnaire was used as was used in both the 1989 and 2014 studies for physicians. A parallel survey for non-physician participants was created, asking comparable questions, but from the perspective of a patient rather than that of a physician. I comparatively analyze the knowledge of individuals and physicians concerning advance directives, different factors important to them in their end-of-life healthcare decision-making, and aspects of their patient-doctor relationship(s) that may account for these discrepancies between the two groups in regards to end-of-life healthcare decision-making.

Further, studies have suggested two issues relevant to advance directives: 1) living wills have turned out to be insufficient guides to directing end-of-life care and 2) physicians choose less heroic end-of-life healthcare options for themselves than they do for their patients (Winter,

Parks, & Diamond, 2010; Periyakoil et al., 2014). Less conservative treatment options may be chosen by physicians for their patients due to physicians' experiences in the medical field, the current culture of biomedicine which rewards high-tech care over realism in end-of-life care, and the void or strain in communication between physician and patient (Kleyman, 2014). This is an area of concern due to excessive spending for unwanted treatments and more importantly, it brings to question whether or not human dignity is respected and maintained at the end of life. From an economic standpoint, spending at the end of life is disproportionate with outcomes and individuals' wishes. Federal spending on healthcare in the U.S. accounts for about 18 percent of the United State's national output. Of this 18 percent, Medicare spending amounted to about 21 percent, or \$554 billion in 2011. About \$170 billion of this amount was spent on patients' last six months of life, and unwanted treatment at the end of life is a prevalent area of concern (Pasternak, 2013; Atkins, 2014). In other words, the federal government is spending an extraordinary amount of money on end-of-life healthcare measures that are broadly unwanted.

Few qualitative analyses have been done on non-physicians and particularly on physicians to understand their background knowledge and experience regarding advance directives, and to understand factors important in their end-of-life healthcare decision-making. From the limited literature available qualitatively examining end-of-life care, disparities do exist along the lines of education, socioeconomic status and race among other factors in regards to end-of-life healthcare (Evans & Ume, 2012). These disparities also exist between those who work in the healthcare field, notably physicians, who are knowledgeable on end-of-life matters versus those who are removed from the subject and not well-informed (non-physicians for the purpose of this study).



This study will examine why advance directives in healthcare have turned out to be unsatisfactory in fulfilling their purpose, as well as why there exists a significant disparity between end-of-life healthcare decision-making and planning for non-physicians versus those of physicians. The quantitative component will follow previous studies of physicians using a 14-item AD questionnaire (Davidson *et al.*, 1989; Periyakoil *et al.*, 2014). These responses will be compared with responses of non-physician participants. Based on my analysis, I will seek to understand the key factors driving end-of-life decision-making. This new information can be used to help guide public health experts in writing policies to improve communication between physicians and their patients. Results of this study may also be used to manage federal healthcare spending at the end of life, and to increase effectiveness and accuracy while respecting patients' wishes in dealing with end-of-life healthcare measures. Finally, this study can additionally provide more insight on the current role of advance directives, end-of-life decision-making and patient-doctor relationships in the U.S. healthcare system.

My analysis will begin with a brief discussion of existing research and theory to identify ways in which my study can contribute to the existing literature. From this analysis, I will develop a conceptual model for the purpose of providing a comprehensible framework for my hypothesis. I will then provide a detailed description of my research methods. Next, I will summarize and present my qualitative research results. Lastly, I will discuss my findings, the limitations of my study, as well as the potential implications of my research to public health policy and medical practice.

## **CHAPTER 2: BACKGROUND AND CONCEPTUAL FRAMEWORK**

Advance directives as they stand in the current United States healthcare system are a method of healthcare utilization that refers to both the power of attorney for health care and the

healthcare living will. These documents differ from state to state, and every adult may complete a living will and choose a healthcare power of attorney in the absence of a lawyer. Advance directive documents can be located online through the US Living Will Registry (“Advance Directives/Living Will”). Despite advance directive creation being open to everyone, their usage is not widespread. Literature indicates that only between 18% and 30% of Americans have completed an advance directive (Wilkinson, Wenger, & Shugarman, 2007). Although information on the prevalence of advance directive usage among physicians themselves is lacking, following that more educated individuals are more likely to use advance directives, physicians may be more likely to utilize advance directives as they are more aware of them and of their terms and have achieved higher levels of education. The high income of physicians is another contributing factor to physicians being more likely to complete advance directives (Rao, Anderson, Lin, & Laux, 2014). Acquisition of information and knowledge regarding advance directives can come from a variety of sources including family and friends, physicians, and/or other healthcare providers.

A framework for viewing health services utilization as well as four primary decision-making framework models contribute to an understanding of an analysis of end-of-life healthcare decision-making. The health services utilization framework contributes to our understanding of individuals’ decision-making at the end of life, while the decision-making framework models present an overview of patient-doctor interaction and dynamics that can guide the conversation regarding death and end-of-life healthcare.

In terms of decision-making, health services utilization (including end-of-life healthcare services use and the selection of the terms of advance directives) is a function of five different factors: sociocultural, sociodemographic, social-psychological, organizational, and social

systems (Anderson, 1973). These factors each influence how individuals think about their end-of-life care, and if and how they go about seeking advance directives. Social determinants, such as relationships with family members and educational background on advance directives work with health services systems and individual determinants to guide if and how individuals choose advance directives. These factors may differ between non-physicians and physicians. Looking at end-of-life healthcare decision-making through the perspective of these utilization frameworks helps us gain a better understanding of what factors drive patients to engage in the healthcare system in regards to end-of-life healthcare, as well as the extent to which they do so.

Referring to the framework for viewing health services utilization proposed by Andersen and Newman (2005), social determinants and norms coupled with healthcare service infrastructure and individual determinants influence an individual's health services utilization. With respect to end-of-life care, key determinants may include individual characteristics such as income, legal access to healthcare services, education, religion and race. Further, the family and peer environment may contribute to social norms in terms of healthcare decision-making, and experience as well as the social and family environment likely contribute to how individuals have been normalized to utilize their healthcare systems and consider end-of-life care for themselves and for their loved ones. Finally, the patient-doctor relationship may serve as an enabling factor in end-of-life healthcare decision-making. This relationship may additionally contribute to a patient's healthcare resource knowledge and utilization. Strong patient-doctor relationships are characterized by high levels of trust and may lead to increased knowledge on healthcare services and increased healthcare services utilization, as they have been shown to influence the communication of information between doctor and patient (Hall, Roter & Katz, 1988). Overall, the three factors of individual characteristics, family and peer environment and

the patient-doctor relationship will be studied as the primary considerations to be examined in this study insofar as they contribute to end-of-life healthcare decision-making.

When examining the success or lack thereof of advance directives, individuals' considerations in advance planning contribute to discrepancies between end-of-life healthcare treatment decisions of non-physicians versus those of physicians. To understand these discrepancies, individuals' backgrounds and knowledge pertaining to end-of-life care are assessed for each group respectively. In terms of non-physicians, factors including but not limited to cultural values, religious beliefs, and family support systems heavily influence how and if individuals complete advance directives, and the extent to which they do so (Hinders, 2012). Rather than taking a scientific approach based on data and physicians' knowledge, patients make decisions and plan advance directives with their autonomy and trust with physicians and/or with the healthcare system held as top priorities (Becker, Jaspers, King, Radbruch, Voltz, & Nauck, 2010). Although there is significantly less published research available on the topic of physicians' personal end-of-life healthcare decision-making, the limited studies conducted suggest that most physicians would choose relatively much more conservative end-of-life healthcare measures for themselves when terminally ill, yet they tend to pursue aggressive, life-prolonging treatment for their patients facing the same prognoses (Periyakoil et al., 2014). Physicians' extensive medical knowledge and experience on what works and what does not work are likely reasons for this discrepancy.

Drawing upon the four models of the physician-patient relationship as proposed by Emanuel and Emanuel (1992), each structural relationship is characterized by different terms that alter the dynamics of healthcare decision-making. These structural relationships contribute greatly to not only how patients learn about end-of-life care, but also to why patients and/or

physicians make the decisions they do. This study will investigate if patient-doctor relationships built around a specific one of these four frameworks inclines patients to be more likely to have a specific end-of-life healthcare outlook or plan.

The four models of physician-patient relationships proposed by Emanuel and Emanuel (1992) include the paternalistic model, the informative model, the interpretive model, and the deliberative model. The physician essentially making decisions in what he/she sees as the best healthcare interest of the patients characterizes the paternalistic model, which is a traditional model of decision-making where the physician takes on an authoritative role, placing health above choice. The informative model differs in that it emphasizes choice, giving patients the primary autonomy in making their healthcare decisions, after being informed by their physicians on their available options. The interpretive model represents more of a partnership in decision-making, while the deliberative model is centered on the physician working with the patient to choose a treatment that aligns most closely with his/her health-related values. Perhaps in patient-doctor relationships in which the physician has a traditional role, having an open discussion about advance directives and about end-of-life care is difficult and may lead to an adversarial relationship between patients and their physicians. The informative, interpretive and deliberative models all are more in accordance with a prioritization for patient autonomy and healthcare that is centered on patients' wants.

In this study on end-of-life healthcare decision-making, the healthcare utilization framework and the frameworks of patient-doctor relationships have been taken into account as they apply to the Davidson et al. (1989) and Periyakoil et al. (2014) studies. The frameworks are used to analyze the factors that contribute to the discrepancy between patients' end-of-life healthcare as opposed to the end-of-life healthcare of physicians themselves. According to

Periyakoil et al., 88.3 percent of the approximately 1,100 physicians surveyed said that they would reject heroic end-of-life treatment for themselves and instead opt for comfort care.

Periyakoil et al's (2014) study also highlighted differences across specialty, gender and race in regards to opinions on advance directives—something that had not been done previously in the study by Davidson et al. This study will seek to examine why these physicians opt for comfort care, as well as why unwanted and costly heroic end-of-life healthcare measures are so frequently taken for patients when they are not wanted and often not taken by physicians in their own end-of-life healthcare decision-making (as explained by Periyakoil et al).

This study will primarily use a qualitative approach to look at end-of-life healthcare decision-making and attitudes on advance directives from both the physician and non-physician (patient) perspectives, the former which is largely unexamined. The 1989 Davidson et al. study and the 2013 Periyakoil et al. study solely use a quantitative approach to examine physicians' attitudes towards advance directives. Questions still remain as to what factors may affect decision-making, and on a broader scale, why the personal end-of-life healthcare plans and decisions of physicians may vary greatly from those of non-physicians. In this study, individuals and physicians will be surveyed and interviewed on the topics of advance directives, decision-making, and the patient-doctor relationship in order to get a better understanding of the differences in the thought processes of non-physician individuals and physicians when it comes to healthcare decisions at the end of life.

## **CHAPTER 3: METHODS**

### **Data and Procedures**

Survey-based data collection was used, followed by qualitative interviewing. Ten non-physicians primarily living in retirement communities in the Chapel Hill/Durham, North



Carolina area were recruited and interviewed. Ten physicians from this general region were also recruited and interviewed. Recruitment was done primarily via email to local retirement community offices and to local physicians and physicians offices and later followed-up by telephone calls. After some initial contacts were established, a snowball sampling effect took place.

Two different brief five-minute pen and paper surveys were administered prior to each interview—one for physicians and one for non-physicians. Following the survey, a one-hour long interview was conducted on three primary topics of consideration: advance directives, factors taken into consideration in end-of-life healthcare decision-making, and the dynamics of the patient-doctor relationship. All non-physician interviews were conducted in person, while some physician interviews were conducted over the phone. Most data were collected in the Durham/Chapel Hill area from December 2014 to February 2015.

### Participants

In this study, ten non-physicians were interviewed, all of who were over age 65 and living in private retirement living communities (**Table 1**). Of the non-physician participants 80% (N=8) identified as Caucasian while 20% identified as African-American. There were five female participants and five male participants in this group, all of who identified as members of the Christian faith. All non-physician individuals in this study had no prior work experience in a health-related profession.

**Table 1.** Demographic Characteristics of Non-Physicians

Pseudonym	Gender	Age	Race	Past Field of Work
Frank	M	<80	Caucasian	Military
John	M	>85	Caucasian	Sales
Louise	F	80-85	Caucasian	Clerical
Beatrice	F	>85	Caucasian	Education
Ellen	F	80-85	Caucasian	Computer Programming/Missionary
Mark	M	>85	Caucasian	Military/Education
Hector	M	<80	African-American	Military
Anne	F	80-85	Caucasian	Computer Programming
Henry	M	>85	Caucasian	Journalism
Marie	F	80-85	African-American	Education

Additionally, ten physicians from a variety of specialties were recruited and participated in this study, including six from Family & Internal Medicine, 1 from Pathology, 2 from Gastroenterology, and 1 from Surgery (**Table 2**). Nine out of the ten physicians in this study worked as part of a greater healthcare institution, while one worked at a private practice. Three were female, seven were male, and nine identified as white while one identified as other.

**Table 2.** Demographic Characteristics of Physicians

Pseudonym	Gender	Age	Race	Specialty
Dr. Smith	F	55-60	Caucasian	Internal Medicine
Dr. Jones	F	<55	Caucasian	Family Medicine
Dr. Frank	M	>60	Caucasian	Family Medicine
Dr. King	M	55-60	Caucasian	Internal Medicine
Dr. Flag	M	55-60	Caucasian	Gastroenterology
Dr. Jamision	M	55-60	Other	Pathology
Dr. Alice	F	<55	Caucasian	Family Medicine
Dr. Cameron	M	<55	Caucasian	Surgery
Dr. Black	M	<55	Caucasian	Family Medicine
Dr. Gold	M	>60	Caucasian	Gastroenterology

## Procedures

As the Principal Investigator, I conducted interviews of physicians at locations at the convenience of the interviewee or over the telephone for physician participants whose busy schedules made scheduling an interview slot very challenging. These locations included UNC Hospitals, Duke Regional Hospital, Carrboro Pediatrics and Internal Medicine, and Chapel Hill Primary Care. Interviews of non-physician individuals were primarily conducted at the Emerald Pond retirement community in Durham, North Carolina. A brief pen-and-paper questionnaire survey was given, followed by a conversation-like verbal interview consisting of ten primary questions and lasting approximately one hour. Both the brief survey and the conversation guides contained different questions for the physician and the non-physician groups of participants (**Appendices**). Verbal consent was acquired prior to beginning interviews and obtaining recordings. Interviews were recorded using one recorder. Prior to conducting interviews, this

study and all materials were reviewed and approved by the UNC-Chapel Hill Institutional Review Board.

### **Data Analysis**

After the completion of the interviews, survey responses were analyzed for major emerging themes. Interviews were then transcribed for additional analysis. Transcripts were coded and reviewed to identify themes in responses in each of the two groups respectively, as well as to identify differences between the two groups. Interviewing and transcribing was done following the models set out by Robert Stuart Weiss in *Learning From Strangers: The Art and Method of Qualitative Interview Studies*.

## **CHAPTER 4: RESULTS**

### **Non-Physician Participants**

Throughout my research and analysis, three main topics were discussed with elderly individuals in the non-physician group. These topics were advance directives, decision-making, and the patient-doctor relationship. Within each of these topics, I examined each individual's opinions and knowledge. Both the *Non-Physician's Advance Directives Attitude Questionnaire* and the interview portion regarding advance directives addressed participants' basic understanding and sources of information regarding advance directives in healthcare, as well as their primary wishes and the way that they prioritized those wishes. When addressing decision-making, fear of death, religious beliefs and lack of knowledge regarding advance directives emerged as the most influential factors in the decision-making of the non-physician group of participants (**Table 3**). Lastly, the dynamics of each individual's relationship with his/her

**Table 3.** Themes in End of Life Care of Non-Physician Participants

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#### **1. Advance Directives**

#### **2. Decision-Making**

2a. Fear of Death and Readiness to Die

2b. Religion and Belief in the Afterlife

2c. Limited Knowledge and Information about Advance Directives

#### **3. Patient-Doctor Relationship**

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physicians was addressed.

### Advance Directives

80% of non-physician participants (N=10) reported knowing what an advance directive was, while only 50% reported actually ever having talked to their doctor about an advance directive (**Table 4**).

**Table 4.** Non-Physician's Knowledge on Advance Directives

QUESTIONS		Yes	Unsure	No
Do you know what an advance directive is?	N	8	1	1
Has your doctor ever talked to you about an advance directive?	N	5	0	5
		Advance Directive/Proxy	Physician	Other
In a catastrophic situation, I would feel most comfortable if decisions were made according to:	N	7	2	1

All non-physician participants expressed having heard about advance directives over time as a part of their lives through normal conversations not held with their doctors, such as with family members, friends, or in the workplace. Rather than being familiar with the distinct documents regarding advance directives and what they specifically report, participants mostly had a vague understanding of the official documentation of advance directives, as Frank expressed regarding his knowledge of advance directives:

(I know) not as much as I need to know, but, or as I would like to know, but I have already made my decision that they will not try to resuscitate me [Frank].

This expression is a reflection of the limited understanding regarding the specifics of advance directives. In this way, end-of-life healthcare decisions and the purpose of advance directives are viewed in a binary way—simply let live or do not let live regardless of what the individual's specific health outcomes and living conditions become. Discussion of being a “vegetable” was frequent, referring to a persistent vegetative state without a nuanced understanding of what a “vegetables state” might encompass:

I said before, I don't want to lay there and be a vegetable and vegetate for 20-30 years. Do what you can for me, and then it is time to go [Mark].

Participants' life backgrounds and past careers played a role in their acquisition of knowledge and outlooks on advance directives. Several individuals with military backgrounds noted both being introduced to advance directives and filling them out while in the military. In the military they had become familiar with issues pertaining to death and became comfortable discussing end-of-life issues. As Mark shared:

I was in the Navy for 21 years. And I flew both propellers and jets off carriers and lots of people died. And we are very familiar with that and we know it, and it is just a part of our life. So I don't go sitting around going what'll I do now, what'll I do now? I know what I wanted to do, and I did it [Mark].

Those participants who did not come from military backgrounds were more likely to show some discomfort when discussing mortality. When conversing on their end-of-life wishes, non-military participants frequently reflected on the uncertainty of death. Some were not exactly sure what end-of-life treatments they would want or be comfortable with, making it more difficult to actively plan ahead of time and create advance directives. At the same time, there was also an expression of concern that families may want to take measures for their loved ones that are different from what the individuals themselves would want in their own end-of-life healthcare. Deciding when to stop treatment is a challenge for individuals themselves, their families, and physicians alike. As John explained:

There are some doctors that want to try anything and everything. I would within reason. But when it gets beyond reason then I wouldn't [John].

This sense of reason regarding how much medical care is too much care is difficult to define, arbitrary and ever-changing in the minds of patients, their families, and their physicians, which further complicates adequately preparing a decisive advance directive. Another participant, Louise, shared an example of a situation in which she would choose to withhold treatment:

I think whether what you have is terminal, if you know it's terminal, that would be a big factor in saying no I don't want to be. But if there is some chance, if the doctor thinks there's a chance, even a small chance, 5% chance of a cure, then I don't know... Well I think if you're 90 years old, no, I wouldn't go with a 5% chance. 40? 40, yeah, because I would want a chance of living a full life [Louise].

Nonetheless, she goes on to reiterate the uncertainty of advance planning in end-of-life care:

And you don't really know how you are going to feel until you are in that situation. Big difference in thinking about it and being in it [Louise].

In thinking about the importance of advance directives, individuals expressed the view that they are imperative and meaningful to complete. Despite this, many were not well-informed and could not recall talking to their physicians or other healthcare providers about them. When asked to explain the reasons as to why they had not spoken about advance directives with their physicians, participants identified two key reasons. First, they did not have enough time during appointments with their physicians to have a thoughtful discussion on the topic. Second, they found it difficult to talk about the topic of death with family and friends. As Henry summarizes:

I don't hear a lot of talk about it (advance directives), it hasn't been brought up to me very often, but I haven't heard anything negative...it is unpleasant to talk about because it's, it you know brings you face to face with the end [Henry].

A final concern regarding advance directives noted by the non-physician participants was that they had difficulty knowing and deciding when to terminate all treatments. Deciding whether or not to take a chance on a treatment often arises as a difficult decision to be made by the patients and/or their families. As Ellen recalls:

Well I just lost a dear friend of over 50 years, and she had been diagnosed, didn't have that many symptoms or anything, with a brain tumor. It was so deep-seeded that they couldn't do surgery. And, but they told her that if she took chemotherapy it would give her 14 months of life. After going through all of the treatments, she was granted 2 months. Granted, she was older, but I still think you have to weigh what are the odds. What are the statistics on the treatment being that good? Or is that just an added expense and basically a research study? [Ellen]



Without the adequate expertise or advice from their physicians, patients have a difficult time knowing whether or not to stop undergoing further treatments that may prolong their lives but not provide them with any valuable quality of life. Medicine today favors treatment after treatment, and the suggestion of withholding treatments often raises legal and bioethical questions (Emanuel, 1988). However, as Marie explains, not only is heroic treatment often times unnecessary and unbearable by the individual, it is also not something that she is in favor of:

Because it is hard on the family, I think it is, and often times it can go on and on and on and not be—the person would not be able to decide for themselves, so they need someone to say NO, enough is enough [Marie].

In this sense, advance directives serve an important role in preventing the everlasting continuation of heroic care.

### **Decision-Making**

When individuals translate their knowledge on advance directives to the reality of making documents, their decision-making reflects their true understanding. Participants were asked several questions in the *Advance Directives Attitude Questionnaire* regarding their decision-making on end-of-life care (**Table 5**). Survey responses to the question “I would worry less about unwanted treatment after making an advance directive,” echo individuals’ fears of receiving everlasting heroic care. 100% of non-physician participants in this study indicated that they agreed or strongly agreed with this statement (**Table 5**).

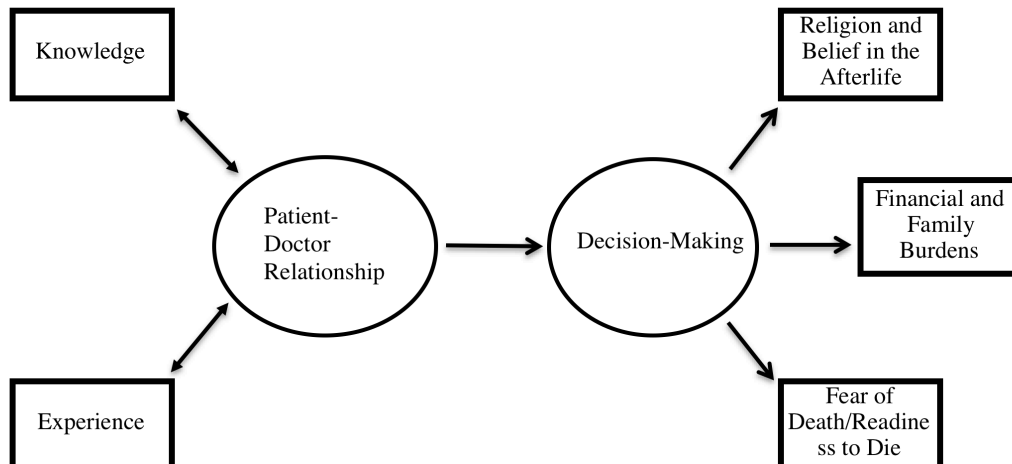
**Table 5.** Non-Physician's Advance Directives Attitude Questionnaire

STATEMENTS	Agree or Strongly Agree, N	Undecided, N	Disagree or Strongly Disagree, N
I feel uncomfortable talking to my primary care physician about advance directives	0	1	9
I feel well informed on advance directives and end-of-life decision-making	8	0	2
I worry that my end-of-life wishes will not be followed	0	0	10
Advance directives represent an unwarranted extension of the law into the practice of medicine	3	1	6
It is likely that I may change my mind about end-of-life treatment from what I initially indicate on my advance directive if I were to become terminally ill	1	2	7
The training and experience of physicians give them greater authority than patients in decisions about withholding "heroic" treatment	3	4	3
I would worry less about unwanted treatment after making an advance directive	10	0	0
I take into account medical expenses when thinking about end-of-life treatment	9	0	1

Moreover, 70% of the non-physicians said that in a catastrophic situation, they would feel most comfortable if their healthcare decisions were made by their advance directive or healthcare proxy (healthcare power of attorney), while 20% listed their physicians, and the last 10% stated other (**Table 4**).

This high percentage reflects the confidence that patients have in their advance directives and the degree to which they value their autonomy over the discretion of their doctors. A sense of security and confidence is associated with the peace of mind that an individual has consciously created their own advance directive. As shown in **Figure 1**, four factors influenced individual's decisions to complete advance directives: (1) Fear of Death/Readiness to Die, (2) Religion and Belief in the Afterlife, (3) Financial and Family Burdens, and (4) Their physician-patient relationship.

**Figure 1.** Factors Influencing Non-Physicians' Decision-Making Regarding End of Life



### ***Fear of Death and the Readiness to Die***

90 % of elderly participants in this study felt they had lived their lives fully and were prepared to die. Despite expressed fear over remaining in a vegetative state for a prolonged period of time, fear of being dead did not seem to play a significant role for participants.

Explaining her readiness to die, Beatrice commented:

I am old enough to die. I said to my son just this weekend at Christmastime: look, if I drop dead, have a party. Don't mourn me because I am ready to go. All my friends are dying, I can't... I used to be a golfer, I can't play golf anymore, I do still play bridge, but I can't do the things I used to do. I am ready to die any time [Beatrice].

For some participants, the lack of fear regarding death stemmed from a deeply rooted sense of religion and a belief in the afterlife. Frank stated:

There are some people that are afraid, because they don't know him... they don't have any idea what heaven is... So, there's a, I think that's the main reason people are afraid of dying, I really do. Cause they don't know—they don't know what the next step is [Frank].

### ***Religion and Belief in the Afterlife***

While religion did not hinder participants' decisions to complete an advance directive, it did affect their outlook on the appropriateness of heroic measures. Religion did not have a

uniform effect on participants' decision-making. For some who expressed a deep religious connection and a strong belief in the afterlife, they saw advance directives as essential to removing a burden from their families. Without advance directives in place to delineate their decisions, their families would have to make decisions for them and would be placed in stressful situations. For others who shared deep connections to their faith, they explained that whatever death they ended up with was predetermined and predestined for them. As a result, they were ambivalent about indicating what types of medical measures should or should not be taken in their advance directives. Ellen, a Protestant with history working as a missionary, expressed that although she does not want heroic measures taken, she is leaving her fate in God's hands. She explained:

It is ultimately God's decision, and I don't want somebody else interfering when he says it is time...If it's time for me to leave this world, it's time. I don't need any heroic measures. I've had a good life, hopefully I'll have a few more years, since I just got a new great grandbaby to enjoy seeing some of my greats, and I do, I want to see as many of them grow up as long as I can, but I mean I think when God decides it is time for us to come home, it's time [Ellen].

Hector shared this same sentiment:

Well faith, faith tells me that if I got belief in God, then I don't have to worry about if the machine keep me. If God want me to stay long, I'm gonna stay long. Regardless of what the doctor's decision says, what he says about my condition and whether I had a machine or not, my life will go on, the way God was planned for me. My life has been pre-planned [Hector].

Individuals like Ellen and Hector are indirectly making a decision by not making one. By not completing an advance directive, they essentially are choosing maximum care at end of life, the default in modern day medicine in the United States.

### ***Financial and Family Burden***

The decision to prepare advance directives was additionally shaped by concerns (or lack of concern) regarding costs and burdens to patients' families. Financial concerns relevant to

family differed accordingly with family structure and the financial health and work background of the participant. All veterans in this participant sample had access to VA healthcare, and did not report thinking much about costs. They explained that they felt that all of their healthcare needs were met and that they were not concerned with being able to afford treatments they would need or want in the future. By contrast, individuals without access to the VA healthcare (all non-veteran participants in this sample) considered family and financial burdens together. Talking about what she considers most when she thinks about her end-of-life healthcare plans, Louise stated:

I was thinking a lot about my family, I didn't want them to be left with someone that is lingering and lingering and lingering, definitely not someone who is brain dead. I wouldn't want to be helpless, just in a helpless condition because that would pose a lot of problems for them financially and just the emotional strain [Louise].

Likewise, Anne was concerned with the financial burden she could be placing on her family if she chose to undergo heroic treatments that she did not desire:

Well I don't want my children to be burdened with unnecessary costs...I guess you think about will you have enough money to last you the rest of your normal life? Mostly with parents, is they don't want to burden their children. Well I say most as a generality too. I wouldn't want to burden my children with unnecessary treatment [Anne].

### ***Patient-Doctor Relationship***

Non-physicians in this study described their relationships with their physicians in terms of both time and trust or closeness. Nearly all participants mentioned feeling pressed for time in situations with their physicians, making it challenging to have meaningful conversations on their end-of-life. Feeling pressed for time also made it less likely for patients to find out what types of documents they should be accessing, how to access them, and the nuances that exist among specific end-of-life options. Despite this variation, no participants reported feeling afraid or uneasy about having a discussion regarding advance directives or end-of-life healthcare planning

with their physicians once the time constraint element was not considered. As aforementioned, only 50% of participants reported that their doctor had ever talked to them about an advance directive (**Table 4**). They did not ask about advanced directives because of time constraints. As Frank explained:

I realize how much time it takes to do that kind of stuff, and she (the physician) is a very, very, very, busy person taking care of those veterans. And I don't want to take any more time from her than I have to... If I thought that she could afford the time, then I would be very comfortable doing it [Frank].

Individual's willingness to discuss advanced directives with their physicians was also influenced by the degree of closeness or trust they had in their physicians. Some individuals had developed close relationships with doctors that were friends or neighbors. Others reported relocating during their elderly years and experiencing considerable stress as they worked to establishing relationships with new doctors. The doctor's age, specialty, and personal demeanor were all factors that contributed to the patient-doctor relationship dynamic. Physicians who were older and more experienced made it easier for patients to talk about death. Patients also more frequently talked about end-of-life issues with their primary-care providers rather than with specialists. The personal demeanor of physicians varied with physicians' personalities and contributed to the comfort of patients in openly talking about their thoughts and concerns regarding end-of-life care. Marie recounted her experience relocating at an old age and the ways in which her relationships with her doctors changed accordingly with her physicians' ages and personalities:

Well, I have a new doctor, the doctor that I had formerly, I would feel uncomfortable about. That was when I lived in Chicago. A woman, in her 40s. But this new person that I have, I think I would feel comfortable talking about it to her and helping her, have her help me understand what my body is saying now, what situation it is now and what should I be planning as far as life years are concerned. And I think that she would be a good advisor to me. Because I think that with your children, they want you to have everlasting life you know, but I would feel comfortable talking to her about it [Marie].



## Physician Participants

In this section, I summarize what I learned from physicians regarding their knowledge and outlooks on advance directives, decision-making, and the patient-doctor relationship. Both the *Physician's Advance Directives Attitude Questionnaire* (**Table 7**) and the interview portion regarding advance directives addressed physicians' basic understanding and educational background regarding advance directives in healthcare.

Decision-making regarding end-of-life healthcare was investigated from two perspectives: the perspective of the patients' decision-making, and the perspective of the doctors' personal decision-making (**Table 6**). The results of these investigations indicated that patients and their physicians held different priorities in regards to end-of-life issues. Lastly, the doctoring style of each physician was assessed, as well as the dynamics of their relationships with their patients. When addressing decision-making, two key factors emerged as most influential—burdens and the patient-doctor relationship. Lastly, the dynamics of each individual's relationship with his/her physicians was addressed.

**Table 6.** Themes in End of Life Care of Physician Participants

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### 1. Advance Directives

### 2. Decision-Making

2a. Physicians' Decision-Making About Their Patients' End-of-Life Healthcare Choices

2b. Physicians' Decision-Making About Their Personal End-of-Life Healthcare Choices

### 3. Patient-Doctor Relationship

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#### Advance Directives

Physicians reported learning about advance directives from a number of sources. Few had mentioned learning about them in courses related to bioethics in their medical school education, while others reported never having had any sort of formal education on the topic that they could recall. Physicians reported learning from experience throughout their years in practice, as well as

from their mentors in their residencies and fellowships. Dr. Jones, a palliative care specialist noted learning about advance directives briefly in her Family Medicine residency training, followed by a more in-depth education during two months of experience working in Palliative Care during her Geriatrics fellowship. When comparing her education in each she explained:

In my residency training it was really we are going to have a conversation, why don't you watch and learn as opposed to these are some of the basic principles and this is how you should run all the meetings—which is what I learned in my fellowship. It was much more on the fly in my residency [Dr. Jones].

Dr. Jones' explanation of momentary glimpses of advance directive education she received during her residency training is representative of how the other physicians also described their medical training regarding advance directives. Some physicians noted learning about end-of-life issues or advance directives in seminars they attended as part of CME (Continuing Medical Education) conferences, or attending events held by insurance companies. On the whole, practical experience throughout their careers was the primary source of physicians' education on the topic.

All physicians surveyed and interviewed (N=10) were in support of patients creating advance directives. However, while some seemed to be content with the current state of advance directives in North Carolina insofar as they were being filled out and used in practice, many held reservations. No physicians surveyed were opposed to using advance directives as they are now, but some had complaints in regards to their effectiveness and their specificity on end-of-life measures. 80% of physicians surveyed stated that in a catastrophic situation, they would have greater confidence in their treatment decisions if they were following an advance directive, and 100% stated that they would worry less about legal consequences of limiting treatment if they were following an advance directive (**Table 7**). This is a direct reflection of the security that the advance directive provides in the clinical setting. Dr. Smith in particular, who specializes in

Pediatrics and Internal Medicine felt very passionate about the inclusion of a discussion on well-thought out advance directives as part of her practice, as she explained the degree of importance she thinks her colleagues view advance directives with:

I would like to think that they think that it is important, but in what I see when patients come to me from outside, they don't usually come to me with an advance directives being transferred from another physician, so I am assuming that they have never had the conversation. Most of the time when I bring the subject up with patients, they look at me like no one has ever asked them before. Are you kidding? This far into our discussions on compassionate care and palliative care and compassionate care, expensive care and end-of-life bankruptcy, nobody has mentioned that to you? Although I would like to think that my colleagues are having those discussions I guess they are not [Dr. Smith].

From the perspective of several physicians, the importance of conversations on advance directives has increased over the years, as Dr. Black noted:

It is a growing importance, I think that early on it was thought of more of as a thing you needed to do without much engagement of the doctors but as time has gone on I think it has become more important particularly related to the cost and patient advocacy [Dr. Black].

Dr. Gold also reflected on what he sees as the growing importance of discussing advance directives:

I think most of us find it very important to have advance directives, especially for older patients. The Medicare Annual Wellness Visit for patients over 65 has changed doing has made it kind of a requirement which has been good, it is part of the questions we ask towards that so I think most of us find very important to be doing, because we weren't doing it—it wasn't a standard part of our process before. The Medicare Annual Wellness Visit has improved at least bringing that topic up and what we find is that a large percentage of patients have advance directives and living wills and healthcare power of attorneys and those kinds of things and getting it into the record and talking about it is a big step I think [Dr. Gold].

Physicians stated that perhaps the most important role of advance directives is that they open a dialogue about end-of-life care between them, their patients, their patients' families.

I think my colleagues and I are probably at the same place. I think the consensus is that patients get to make these decisions, and that it is our job to facilitate a conversation if at all possible if the patient is competent, and we encourage them to talk to family members, and we facilitate those conversations [Dr. Alice].

Further, physicians noted that the amount of time they spend discussing advance directives with their patients typically increases with the age of the patients. Although it was mentioned that younger patients could benefit from advance directives since they potentially have the most life to lose relative to elderly patients, advance directive conversations are generally only had with patients over the age of 65. As Dr. Gold explained to me:

I think most of us find it very important to have advance directives, especially for older patients. The Medicare Annual Wellness Visit for patients over 65 has changed doing this. It has made it kind of a requirement which has been good, it is part of the questions we ask towards that, so I think most of us find it very important to be doing, because we weren't doing it—it wasn't a standard part of our process before. The Medicare Annual Wellness Visit has improved at least bringing that topic up and what we find is that a large percentage of patients have advance directives and living wills and healthcare power of attorneys and those kinds of things and getting it into the record and talking about it is a big step I think [Dr. Gold].

### **Decision-Making**

In terms of decision-making, physicians elaborated on what they believed to be important considerations their patients take into account when thinking about end-of-life healthcare and when making their advance directives. Physicians explained what they considered in their personal lives, and how their experiences working in the medical field shaped their feelings and views regarding end-of-life healthcare and advance directives—which proved to be different from the considerations of their patients. 100% of physicians surveyed believed that it was important for patients to be able to influence their medical treatment should they lose competence—reflective of the prioritization of patient autonomy as an extension of the patient-centered model of practice which has become more “recognized and popular,” as Dr. Black stated (**Table 7**). The patient-centered model of practice is a model in which the patient's opinion is actively sought by the physician. It represents an open relationship in which the patient is able to express his/her thoughts or concerns to his/her physician (Stewart, 1984).

When asked to think about what factors their patients should or do consider when making end-of-life healthcare decisions, physicians reported thinking about 1) Religion, and 2) Family Proximity and Relations. However, when asked to think about what factors influenced their own end-of-life care choices, physicians reported thinking about their functionality and their dignity.

***Physicians' Decision-Making About Their Patients' End-of-Life Healthcare Choices***

Of the major burdens discussed by the non-physician group of participants, the most critical burden that physicians described as heavily influencing patients' end-of-life healthcare decisions was family. Physicians expressed the view that patients were minimally concerned, with a few exceptional patients, regarding financial costs when it comes to end-of-life healthcare. Further, religion played a large role for patients in the perspective of their physicians.

***Religion***

Physicians did not report a single trend that they saw in patients of a distinct religious background. Rather, they talked about the topic more broadly and in the sense of how important of a role religion played in their patients' decisions regarding end-of-life care. A natural default to spending excessive amounts at the end of life was explained in connection to religion by many physicians, and by Dr. Smith in particular:

For some reason, God's will is never to save money. I think that is where I kind of get the sense of deciding without deciding, like, "I am going to follow the will of God, but since I don't know what that is, you decide". The people who do successfully complete their end-of-life decisions usually respond more to the other motivators. Those are the folks who think about giving their family peace of mind or not chewing up their financial legacy. Mostly just not wanting to do things that are inhumane to themselves so I guess that is more humanistic and somehow they are convinced it is an appropriate stewardship of their life. And I guess it comes down to the people who, from a personality standpoint either believe they have power or don't believe they have power [Dr. Smith].

Following a similar thought process trend that she sees in her patients as well, Dr. Jones shared how patients seem to discuss using religion as a way to defend the decisions they decide to make.

Dr. Jones has seen religion been used in both support for conservative and heroic measures, as she explained:

What I find really interesting is that I will have people tell me that God gave us all this technology to be able to keep them alive as long as we can but then on one hand using God to justify doing everything. I have also had other people say “you know it is in God’s hands, if God wants me to get well, I will get well. I don’t need to be hooked up to a breathing machine or whatever if God means it to happen, it will happen.” And they will use God to say I don’t want all those things so it doesn’t seem to me that religion tells people what to do. People look to religion to confirm what they want to do. I have had people tell me it is not natural, it is not God’s order that people have feeding tubes and people should be hooked up to breathing machines, but other people say God wants us to live and be alive and that is most important and so they want to be trached and have a feeding tube and all that sort of stuff. It really depends and it really depends on them. People often times can use religion to help shield them from making hard choices. You can say in my religion we don’t believe this and so were not doing that, and that lets people not feel guilty about decisions. No one wants their mother to die, nobody wants their father to die nobody wants their spouse their children, their brothers, their sisters to die and that natural inclination is to do as much as possible [Dr. Jones].

This natural inclination for further treatment and not accepting mortality exists on two levels—on the level of the patient individually, and on the level of the family. Elderly patients were generally described by their physicians as having come to terms with death and not being particularly fearful of death itself. Rather, physicians explained that the primary fear they saw was that patients were afraid of suffering immensely, for example by suffocating or choking to death. In terms of patients’ families, families often times have a more difficult time accepting that they are going to lose their loved ones, leading them to often times want to opt for every last resort, even if it makes quality of life worse. As Dr. Gold explained:

I think we find that most people do not want their life to be extended unless it results in quality of life that goes along with that. They don’t want quantity over quality, whereas family members that are not their body, they will take quantity. They find it difficult to make the decision to shorten the duration of life... they want the duration extended even if it will effect the quality of life. So that is the main thing we find—the discrepancy between the person making the decision (the patient) and their family members [Dr. Gold].

### ***Family Proximity and Relations***



The discrepancy between what patients want and what their families want for them becomes even more evident in family structures where family members are living distant from the elder with health concerns. Multiple physicians mentioned this pattern, captured articulately by Dr. Frank:

I think there is a truism that the further a relative lives from the patient, the more they want to keep them alive. The less involved someone is in someone's life, and you can toss a little guilt in there. They say, "you got to do everything, I'm going to fly back home now." It takes a team of physicians who are all comfortable saying the same thing and it's not always easy to get everybody on board [Dr. Frank].

This "same thing" that Dr. Frank is referring to is the decision for doctors to agree that it is in the best interest of the patient to stop further treatment and heroic measures from being taken. This is in the context that the physicians do not see any more treatment as being helpful, rather, it may be harmful and result in a poorer quality of life. Dr. Cameron shared a similar view, also discussing what the situation looks like in terms of a more close family:

I think often times there is guilt involved. I think the closer a family is, the more willing they are to accept that the end is here. A scenario we see very frequently is mom lives with her daughter, daughter sees her get worse every day, every day, worse and worse, mother has a debilitating medical issue pop up, the daughter realizes she has a debilitating medical issue and that (her mother) can't deal with this added medical illness, and agrees that we should let mom pass away peacefully. The other scenario we see just as often is family is out of town, has not seen their parents in like two years, comes into town, kind of won't accept that there has been this steady decline and that a return to good function is not possible, and wants a lot of invasive things done. So I think one thing that is apparent is that the closer the family usually is, the less extreme things they want done at the end of life [Dr. Cameron].

Finally, physicians expressed that if patients do not make an advance directive or are not clear about what they would like in their limited creation of an advance directive, family conflict often arises. Family members may have different assumptions of what their loved ones would want, and lack of direction results in family turmoil while the patient continues to undergo more and more treatment. Both non-physicians and physicians themselves expressed that they value

advance directives in the way that they relieve some of the burden placed on families to make difficult decisions regarding the prolongation of life.

***Problems Identified by Physicians on the End-of-Life Decision Making Process for Patients***

Non-physicians in this study reported feeling comfortable with having advance directives in their current state, as 100% agreed that they would worry less about unwanted treatment after making an advance directive (**Table 5**). Aside from limited timing with their physicians and the void of a close-knit relationship, no other significant trends of problems were presented regarding end-of-life care from the perspective of these elderly non-physician participants.

However, in interviewing these individuals at length, it became quite apparent that a significant problem was that while they reported to know what advance directives were, they did not understand them. Individuals were not aware of the different types of advance directives, what they specified, and the nuances that existed within them. As Dr. Cameron explained:

Well right now, most people come in with advance directives written if they were a vegetable. What would happen to them? And most people answer that question and most people would say I don't want things done to me artificially if I am a vegetable. But they don't address...the severe disability. So what if I am profoundly demented, unable to recognize my family, what if my quality of life is that I am bedbound, unable to participate in activities of daily life? Those questions aren't answered. So for someone to become a true vegetative state is somewhat unusual. I think the situation we find ourselves in a lot of times is an elderly patient who may have been fairly weak and debilitated before coming in with a major illness, then you're in a situation of we can keep them alive, and they are not a vegetable. We can keep them alive and they are not a vegetable but they will have a very poor quality of life from this point forward and be very disabled and be unable to perform their activities of daily life independently [Dr. Cameron].

Additionally, physicians reported reaching barriers with their patients on a psychological level. According to physicians, patients would often times change their minds regarding what end-of-life care measures they would be willing to take when the actual time came to make a decision. This is in discrepancy with what the non-physician group of participants reported, as

only 10% of these individuals agreed with the statement that they it is likely that they may change their minds about end-of-life treatment from what they initially indicate on their advance directive if they were to become terminally ill (**Table 5**). Perhaps since these individuals generally had not had to directly face death, their reported response may not have been an accurate representation of what happens in practice. From the perspective of physicians, as Dr. Frank shared, patients often times are not truly certain of what they want, making advance directives somewhat unreliable:

I truly don't believe any patient knows what they want—with one exception. If the patient has coded and been resuscitated and you ask the patient afterwards “are you glad we resuscitated you?”—I would believe that patient. But most patients don't. I think it's really difficult to know at which point you would be willing to let go. I have had this discussion with friends—at what point? And the horizon changes the closer you get to it [Dr. Frank].

This changing horizon coupled with obstinacy that patients may demonstrate to adhere closely to their personal views makes it difficult for physicians to help direct patients' decision-making towards conclusions backed by scientific research and data outcomes relevant to specific treatments. Physicians repeatedly mentioned the ineffectiveness yet broad use of feeding tubes as an example of a measure commonly wanted by patients yet proven to not be helpful in prolonging or increasing the quality of life:

If you ask (the patient) why you feel that way they will say I will not let my mother starve to death. It is very hard because most medical people know there is data on feeding tubes and that most of the time when somebody needs that at the end of life, you don't really prolong their life even though it is counterintuitive. There is data on a lot of conditions that you don't prolong life like that. But you can't convince the patient's family sometimes because it is more of a philosophical thing of theirs and not a decision or belief they came by out of data, they came to it out of belief. And you cannot logically change someone's mind out of something that they didn't arrive out of logically...some of that is religion but some of it is a belief people have that they attribute to religion, but they think it is their religion. It is very hard to bring actual real facts into those discussions if people are just going to be very committed to what they already believe coming into the hospital. But it is important because you have to respect those things, because it is their life and death [Dr. Flag].

In this way, a patient's autonomy and patient-centered care dominates the discussion on end of life, pushing away from a model of evidence-based medicine.

### ***Physicians' Decision-Making About Their Personal End-of-Life Healthcare Choices***

Physicians were much more hesitant in their responses when asked to share personal outlooks in terms of what they value most for themselves and their families when considering end-of-life healthcare decisions and the creation of advance directives. Nevertheless, two factors that came to light in most of these discussions were having a functional outcome and maintaining personal autonomy and dignity. A functional outcome for physicians meant leading lives in which they did not have to heavily depend on others to assist them in activities of daily living. Physicians often emphasized returning to a level of function that they were at prior to their illness. Personal autonomy and dignity refer to the physician's desire to decide what constitutes a dignified end for themselves. Physicians emphasized the profound importance of having the final say in their own lives, such as Dr. Smith:

Personally I would like to maintain my autonomy and my dignity as long as possible but when it comes to those people who have to make those decisions for me, I don't want them to guess at what I think qualifies as a dignified ending. Because if there is one thing that 35 years in Medicine has taught me, it is that everybody views that differently. We all think we know what dignity is, but it is very, very, very, personal [Dr. Smith].

This sense of autonomy is also important to physicians because it is a representation of their independence. When they are no longer able to make decisions for themselves, they trust in their advance directives and their loved ones to make the decisions that they have chosen for themselves beforehand. In this sense, having advance directives and open conversations in which they are extremely specific in delineating what measures they would and would not like taken is the closest way for physicians to ensure that they will undergo the treatments they want and nothing more. Physicians explained that they have seen so many patients undergo extensive

measures because this is the default, and they did not specify a stopping point. In addition to legal documentation, physicians heavily emphasized having strong and open communication with both their healthcare team and patients' loved ones. Due to the standardization of advance directives, there is no way to cover every possibility, which is where discretion of physicians and family can play a role. As Dr. Jones explained regarding end-of-life healthcare decision-making:

It is very nuanced. Life throws you all these kinds of curve balls. I don't have an answer for all of them but I do have a framework and really the framework is if it is reversible and can get it back to getting me back to myself then its fine but if it is not then I don't want a lot of fuss and I don't want to be put through a heck of a lot [Dr. Jones].

Knowing what they want and being able to both verbalize those thoughts to others and express them through legal documentation are crucial in obeying end-of-life wishes according to physicians. For Dr. Alice, autonomy is also a primary consideration. Maintaining her autonomy is a way to uphold dignity on her own terms at the end of life:

It comes down to autonomy and the potential negative effects of what we do in heroic measures, those heroic measures often confine us to a hospital, separate us from people who care about us and love us and may have very unpleasant physical or psychological, or even spiritual side effects and for me weighing that against is there any realistic hope that we are doing anything besides prolonging...so the older I get the more comfortable I am that I don't want to be aggressive either. And what I really want most likely is to be at home with people that love and care about me and to go quietly and peacefully and I'm not afraid to go [Dr. Alice].

In each individual's definition of dignity on their own terms, expectations for what they choose their life to look like are often times a priority. As mentioned, a common theme discussed by physicians was that of having functional outcomes. Physicians were concerned with whether or not they would be able to regain function and have a quality of life that they were pleased with:

I think the biggest thing is expected functional outcome. And I think that with modern medicine you can keep almost anyone alive. And I think after seeing all of this, you realize that alive is rarely good enough. I think well short of what is over described as medical futility, I would think that things that are unable to return me to a true functional

status where I would be able to recognize my family, interact with them, and perform some activities of daily living would be my standards for what I would want done to me, which I think is very different from what the average patient writes down in an advance directive [Dr. Cameron].

When functionality is lost, the individual and those who are left to care for the individual are affected. This can result in the individual feeling as if though they are becoming a burden, thereby disturbing the quality of life of their own lives as well as the quality of life of their family members and other loved ones.

### **Patient-Doctor Relationship**

The dynamics of the patient-doctor relationship differed across physicians. Doctors with the most sociable demeanors seemed to be more open and comforting in their approach to discussing end-of-life issues, as opposed to those who were more direct in their doctoring styles. Dr. Frank was one such doctor with a very direct doctoring style and seemingly colder personality. He described multiple issues he saw with advance directives today, specifically citing time as the biggest deterrent from talking about advance directives with his patients. After discussing end-of-life issues with him, it became clear that he seemed discouraged from bringing up the topic of advance directives with his patients. He felt as if though he was not seeing direct results that indicated that patients' advance directives were effective. For him and his patients, the avenue to discuss advance directives is not open:

I never paid that much attention to it. I felt like—well, two things: First, that patients never really understood and secondly, that there are so many other things I was being asked to do that there was no way I had time to really deal with it. [Dr. Frank].

In this way, the physicians' outlook on advance directives directly affects the dynamic between patients and physicians surrounding the topic. Regardless of the personality of the physician, 90% of physicians disagreed with the statement that prolonging life is more important

than honoring a patient's request to withhold "heroic" treatment, while 10% were undecided

(Table 7).

**Table 7.** Physician's Advance Directives Attitude Questionnaire

STATEMENTS	Agree or Strongly Agree, N	Undecided, N	Disagree or Strongly Disagree, N
Widespread acceptance of advance directives will lead to less aggressive treatment even of patients who do not have an advance directive	2	1	7
In a catastrophic situation, I would have greater confidence in my treatment decisions if guided by an advance directive	8	0	2
I would worry less about legal consequences of limiting treatment if I were following an advance directive	10	0	0
It is important for patients to be able to influence their medical treatment should they lose competence	10	0	0
Advance directives represent an unwarranted extension of the law into the practice of medicine	0	0	10
A potential problem with advance directives is that patients could change their minds about "heroic" treatment after becoming terminally ill	7	1	2
An advance directive would reduce family discord over decisions to withhold treatment	9	0	1
Advance directives are an effective way for patients to influence their medical treatment should they lose competence	10	0	0
Discussion of an advance directive would produce a more adversarial relationship between me and my patient	0	2	8
The training and experience of physicians give them greater authority than patients in decisions about withholding "heroic" treatment	2	1	7
Prolonging life is more important than honoring a patient's request to withhold "heroic" treatment	0	1	9
Patients would worry less about unwanted treatment after making an advance directive	9	0	1
Widespread use of advance directives could help contain medical expenditures	9	0	1
I am concerned that advance directives will lead to acceptance of euthanasia	1	2	7

Thus, patient autonomy was once again viewed as a priority in the patient-doctor relationship, with the primary role of the doctors in the current model of healthcare being that of facilitator. Dr. Alice explained:

I was trained that this was an issue of patient autonomy. The fact that it might help reduce costs, depending on your perspective might be an added benefit or a negative. Now you have to come to terms with the idea that as a physician, at a certain point in life or in the course of an illness probably 90% of what we do does more harm than good, and just because we can do it doesn't mean we should do it. Regardless of costs [Dr. Alice].

Physicians are able to inform and discuss advance directives with their patients if time allows, but ultimately the decision is the choice of the patients. When the patient is not well-informed, the current default is to heroic measures, often times leading to doing more harm than good, however still respecting patient autonomy by obeying their wishes.

Physicians generally (80%) disagreed with the statement that the discussion of an advance directive would produce a more adversarial relationship between them and their patients, while 20% were unsure about their sentiments regarding this statement (**Table 7**).

Although Dr. Smith views advance directives with a high level of importance and sees them as an imperative part of an elderly patient's communication with her and other physicians, she notes that she suspects that other physicians might not talk about advance directives very much, if at all, with their patients. She explains that time and comfort are the two primary barriers she sees. Perhaps the minority of physicians who believe that discussion of an advance directive will create a more adversarial relationship between themselves and their patients may believe so due to lack of comfort, and a strained patient-doctor relationship. These elements would make it difficult to have this conversation in a context in which the patient feels as if though his/her physician is genuinely interested in his/her well-being. Dr. Smith elaborates on this point:

For me, the driving force about talking about it is I actually care about the person sitting in front of me and I care about what their end of life is like. I have spent a lot of time working to create a space where they are treated with dignity and where they can talk about their fears and all kinds of things—and I would extend that into their end-of-life decisions. How much do you want me to meddle in your end of life? ...just tell us that is what you want, but be conscious about the process, be involved in the process. For me, having the conversation is a moral issue because it is an extension of my demonstrating care in every aspect of their life that touches on healthcare [Dr. Smith].



Dr. Cameron strongly agreed that opening and maintaining a conversation with patients regarding end-of-life issues and advance directives is an important aspect in his relationships with his patients:

I think the best thing is a frank discussion, an in depth discussion between patients and their families so that when they are unable to communicate and the family becomes a decision-maker. The family will know what the patient would have wanted. Otherwise, families will tend to go on the side of more intervention than most people would want for themselves [Dr. Cameron].

For both the ease of conversing about advance directives, and the sake of knowing patients' wishes, building and maintaining an open patient-doctor relationship is fundamental. Because the current healthcare system places patient autonomy as primary, the patient-doctor relationship is the key link between respecting the patients' wishes while applying the doctor's knowledge and expertise to provide necessary and effective treatments that maintain the quality and dignity of life.

***Problems Identified with the End-of-Life Decision Making Process for and by Physicians***

Physicians both explicitly and implicitly shared criticisms of the current system of advance directives as well as negative implications of the existing structure. Time and costs share an intricate relationship which many physicians, particularly primary care physicians feel burdened by. Dr. Smith in particular felt very passionate about this point:

When I first started this practice, hour-long appointments were how we did it we ran a very, very low budget operation so that we could maintain that kind of time. As things have gone on, we have gradually seen the time we spend with our patients being eroded regularly because the overhead goes up and the reimbursement is held down. Now for me—I don't know what other doctors decide to do—it means I can't exist in this model anymore—I have got to go do something else. That is what it means, it is not doctoring to allow myself to be shoved around by financial forces that don't have anything to do with the patient, or a lot of forces that don't further the advancement of the patient [Dr. Smith].

In addition to the time barrier physicians face, education and communication are also primary issues. As relevant to educating patients on advance directives, physicians noted that legal documents in the State of North Carolina regarding advance directives found on the state website are not very user-friendly and are difficult to understand:

When I found the North Carolina Advance Directives Registry I told them (my patients) about that—that is a very cold and unapproachable website unfortunately like every government thing [Dr. Smith].

Dr. Gold even notes:

The North Carolina forms for example are pretty cumbersome and I even find them difficult to understand, so that's one barrier I think we have [Dr. Gold].

The inaccessibility of advance directive documents coupled with restricted appointment times create burdens for patients in learning and acting once they are properly informed. Additionally, physicians can sometimes exacerbate the extent of this problem if they are not able to or do not translate end-of-life issues from medical thoughts and terminology to a language that the average individual may easily understand:

So things are much, much better now we talk to people as doctors from the things doctors need to know, we don't talk to people about the things they may need to know because I do feel like we don't have yet a great way of fully understanding peoples' end-of-life needs like existential issues...[Dr. Jones].

Further, in addition to the divide in communication between physicians and their patients, physicians also noted the increased fragmentation of healthcare as a contributor to why there is an enhanced discord between patients and their physicians. With the increased place for hospitalists and the removal of primary-care physicians from the hospital setting over the last two decades, the relationship and reciprocated trust in the patient-doctor relationship no longer has a place:

Now, you could have a patient that could in one week see more (physicians) than they would have seen in their lifetime in the hospitals (in the 1980s). So the fragmentation of

healthcare has made it difficult for doctors and patients to make adequate decisions... The issue is trust—and like that guy said they don't know me, I don't know them they don't trust me, I don't trust them. But that could be in any one of these discussions whether you say okay if they find him pulseless or breathless we are not going to resuscitate him. To me they would say okay, to him, they would say no. They think they're trying to kill him, seriously that's what a lot of patient's families will say. Like when I say we are trying to get on hospice, some of them because they know me will trust it but some of them will say if you have a third party in there the third party will say they're trying to kill you [Dr. King].

The near removal of trust between patient and doctor when care is suddenly put in the hands of hospitalists often pushes patients to endure more life-prolonging treatments and opt for more heroic measures at the end of life, further contributing to this trend.

## **CHAPTER 5: CONCLUSIONS**

This study examined the decision-making of non-physician individuals and that of physicians surrounding end-of-life healthcare, particularly relevant to advance directives. I identified the opinions and knowledge of individuals surrounding these topics. A number of factors and the patient-doctor relationship emerged as the biggest barriers in the decision-making process of non-physicians. These factors included the fear of death and readiness to die, religion and belief in the afterlife, financial burdens and family burdens. A primary aim was to address why physicians made relatively more conservative end-of-life decisions than non-physician individuals do. Addressing how and why these differences exist was of principal importance.

Physicians' views on end-of-life healthcare and on advance directives were heavily swayed by their experiences and knowledge on medicine based on their experiences in the field dealing with patients at the end of life. When assessing their attitudes towards end-of-life care for their patients versus end-of-life care plans for themselves, it was evident that the terms of each significantly differed. The prioritization of patient autonomy in a system where the default of individuals' treatment plans is for the most heroic and extensive treatments is often times why

this gap remains. This factor, coupled with families having a difficult time letting go of loved ones and people generally being ill-informed regarding advance directives and end-of-life healthcare options are two other factors that contribute to the prolongation of individuals' lives. Physicians also shared the different factors that seem to most drive decision-making with their patients as well as the factors that drive their personal end-of-life healthcare decision-making. While patients were often times concerned with the external burdens in their lives and allowed this to guide their decision-making, physicians were most focused on functionality when it came to their own end of life. Again, physicians' background and knowledge on end-of-life care guided them towards more conservative end-of-life healthcare decision-making and was the primary reason for this discrepancy.

### **Strengths and Limitations**

A major strength of this study was that it explores both non-physicians and physicians' attitudes towards advance directives and the topic of end-of-life decision-making comparatively. Similar surveys and guided interview questions for the two groups allow for the much larger question at hand to be examined on the level of knowledge, opinions and experience for both groups. This approach made it apparent as to where the differences lie in considerations and prioritization of factors that lead physicians to often times be more conservative in their end-of-life healthcare decision-making approach as relevant to their personal lives. Another key strength of this study was that it provides insight into physicians' opinions and feelings on the current system of advance directives in the United States, along with feedback on their effectiveness and shortcomings. Past research on this topic has led to the same conclusions regarding a more conservative approach taken by physicians, yet it has not sufficiently and thoroughly examined these questions on a deeper level using qualitative methods.

Although this research has its strengths, it also has several limitations that provide room for further research to be conducted on the topic of non-physicians versus physicians' end-of-life healthcare decision-making. First, this research study was cross-sectional and addressed a sample that was limited in its scope and perhaps not representative of the larger population of non-physician individuals and physicians living and working in the United States. The majority of research participants in both the non-physician and physician groups have been living and working in North Carolina for many years. The individuals in the group of non-physicians all live in retirement communities, and the physicians primarily work in the Chapel Hill/Durham, North Carolina area. These may be factors of self-selection towards certain trends in responses. More research is needed to understand national trends in responses, especially as they relate to different patient demographics depending on socioeconomic status, race, and other factors. Secondly, both groups of participants were not asked to fill out advance directive forms that were collected or to complete a questionnaire asking specific questions about what end-of-life measures they would take and/or would not take. This could have provided a more concrete idea of relatively how much more conservative physicians are when it comes to their own end-of-life care decision-making. Due to the small sample size used in this study, the results are not generalizable. However, participants still provided valuable insight on their outlooks regarding advance directives. Perhaps additional qualitative studies addressing similar questions conducted more widely in the region or in the United States may lead to more generalizable results if similar conclusions are reached.

Based off of the valuable feedback provided in particular in this study, both non-physicians and physicians exposed problems in the current design and implementation of advance directives. These problems, as mentioned, include strains in the patient-doctor

relationship, lack of understanding regarding advance directives and end-of-life healthcare on behalf of non-physicians, obstinate views of individuals, physicians feeling burdened by limited time, the inaccessibility of the system, and the increased fragmentation of healthcare. Taking these issues into account, if further research pinpoints the same troubles, policy-making efforts may be directed towards recreating a more detailed and user-friendly method of making advance directives in the United States for patient use. Further analysis can be done to assess the preparation of physicians in discussing advance directives, and to see if the education they are receiving on this topic is effective in practice. Lastly, the fragmentation of healthcare and the changed role of primary-care physicians and growing emphasis on the use of hospitalists is another problem in itself within the domestic healthcare system. Although the implications of this fragmentation contribute to the deterioration of trust in the patient-doctor relationship, the scope of this problem lies outside of this analysis on advance directives, but would additionally be worth analyzing.

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**APPENDIX 1**  
**CONVERSATION GUIDE FOR NON-PHYSICIAN PARTICIPANTS**

**Advance Directives**

- 1) Where have you learned about advance directives in healthcare?
- 2) How important do you think people think it is to have advance directives?
- 3) What experiences do you think shape this view?
- 4) How important do you think it is for people to have advance directives?

**Decision-Making**

- 5) What do you think are important considerations when people make advance directives?
- 6) What do you consider? (Religion? Costs? Family? Fear?)
- 7) From your experiences thus far, what are the biggest struggles (if any) that you find in planning or making end-of-life decisions for yourself or others?

**Patient/Doctor Relationship**

- 8) How difficult is it to have a conversation about advance directives with your doctor(s) and/or healthcare providers?
- 9) Have you found any resources to be particularly effective in learning about end-of-life decision-making? On advance directives?
- 10) What advice would you give to friends in developing their own advance directives?

## **APPENDIX 2**

### **CONVERSATION GUIDE FOR PHYSICIAN PARTICIPANTS**

#### **Advance Directives**

- 11) What if any education did you receive regarding advance directives in healthcare?
- 12) How important do you think your colleagues think it is for patients to have advance directives?
- 13) What experiences do you think shape this view?
- 14) How important do you think it is for patients to have advance directives?

#### **Decision-Making**

- 15) What do you think are important considerations when people make advance directives?
- 16) What do you consider? (Religion? Costs? Family? Fear?)
- 17) How have your experiences as a physician shaped your feelings or views on advance directives and end-of-life decision-making?

#### **Patient/Doctor Relationship**

- 18) How difficult is it to have a conversation about advance directives in the medical setting with your patients?
- 19) What is the best resource to educate physicians, healthcare providers and/or patients on end-of-life decision-making? On advance directives?
- 20) What advice would you give to colleagues or patients developing their own advance directives?