12-2020

A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions

Erin Mauck
East Tennessee State University

Recommended Citation

Mauck, Erin, "A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions" (2020). *Electronic Theses and Dissertations.* Paper 3846. https://dc.etsu.edu/etd/3846

A Qualitative Analysis of End-of-Life Healthcare in Tennessee:

Politics, Principles, and Perceptions

A dissertation

presented to

the faculty of the College of Public Health

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Doctor of Public Health with a concentration in Community Health

---

by

Erin Elizabeth Mauck

December 2020

Dr. Deborah Slawson, Chair

Dr. Roger Blackwell

Dr. Martha Copp

Keywords: end-of-life healthcare, caregiver support, advance directives, Tennessee, policy, death and dying, motivation, funding

ABSTRACT

A Qualitative Analysis of End-of-Life Healthcare in Tennessee:

Politics, Principles, and Perceptions

by

Erin Elizabeth Mauck

The unprecedented growth of the aging population in Tennessee is a significant demographic trend that highlights the necessity for healthcare policy that tackles end-of-life issues. This study examined the perceived quality of end-of-life healthcare in Tennessee, areas that are in need of improvement, policies that have the potential to influence improvements, and the role of politics in end-of-life healthcare policy. It also assessed the support for end-of-life healthcare policy that would advance quality of care and expand end-of-life choices for Tennesseans, while evaluating the policy-making process that legislators employ.

For this study, data were collected using semi-structured, in-depth interviews with an open interview guide. These interviews were conducted in a two-tiered format. Tier 1 included ten leading experts in various areas of end-of-life healthcare and aging in Tennessee. Tier 2 included nine legislators who were members of the health committees of either the Tennessee House of Representatives or the Tennessee Senate. Qualitative data were organized into numerous categories, and an initial phase of open coding was completed. From this phase of coding, emergent themes and focuses were discovered. This was followed by focused coding on all nineteen interviews using coding software to organize subtleties.

Findings of the Tier 1 interviews indicated that there are many areas of end-of-life healthcare that need improvement including increased funding, expanded caregiver support, improved doctor-patient communication, and increased use of advance directives. Emergent themes included the influence of money, having difficult conversations, the stigma of death and dying, and supporting the caregiver. Tier 2 findings highlighted the motivations behind voting decisions and the level of awareness legislators have in areas of end-of-life healthcare policy. Both tiers also explored the support and opposition of physician-assisted death.

The findings of this dissertation are intended to inform health professionals and state legislators. The data gathered through this exploratory research and the knowledge gained will lead to a greater understanding of end-of-life healthcare in Tennessee, and what needs to be done to improve its quality. This will allow individuals and families faced with end-of-life decisions to navigate the process with expanded options, access, and support.

DEDICATION

My research is dedicated to the memory of my grandmother, whose lifelong guidance, generosity, and friendship made this research possible. It is because of her that I was able to return to college in 2010 when she opened her heart and home to my family and encouraged me through the attainment of three degrees. Throughout my life she taught me the importance of being able to support myself, that I need to take care of my physical health because I may live to be 100, and to always hold my head high even when times get tough.

Mildred Yeager Cooper

August 25, 1924 – April 4, 2020

ACKNOWLEDGEMENTS

I will be forever grateful to the people in my life who have made this dissertation possible. From day one, I have had unconditional support from family, friends, faculty, and even from people whom I met only briefly. First, I would like to thank my family for their understanding of my busy schedule, their enthusiasm for my research, and their willingness to talk about end-of-life healthcare for countless hours. I want to thank Andy for encouraging me on a daily basis, even when I felt like I had nothing left in me to give. When I had days where I felt I would never finish, he gave me the nudge to stay focused and complete what I had started. His unwavering support and love were integral to the completion of this dissertation. I also want to thank my daughter Katie who has been listening to me talk about death and dying for eight years, but still participates in the conversations with interest. She helped me celebrate the triumphs and cry through the setbacks this past year as I was collecting my data. She traveled to Nashville twice with me for support and was such an important part of this experience. I would like to thank my sister Ashley for always being only a phone call away when I needed someone to tell me everything would be okay, and when I needed to vent my frustrations so I could get back on track, she was there. To my son Wyatt for his continued support, and my dad and Uncle Jerry who have cheered me on without hesitation in all my educational endeavors, and for being two of my biggest supporters and role models.

I would also like to thank the faculty and staff of the College of Public Health at ETSU. There have been so many different people who have influenced my research and the writing of this dissertation. I want to thank the members of my committee; Dr. Slawson, Dr. Blackwell, and Dr. Copp. Each of them contributed to the success of this research in different ways, and I am so appreciative. Specifically, I want to say thank you to Dr. Slawson for all of the support she gave

me throughout the writing of this dissertation. This past spring, she encouraged me through significant setbacks, including the death of my grandmother and the coronavirus. During one particular email, she told me to allow myself some grace. That one comment gave me the permission I needed to heal at my own pace, and for that I will be forever grateful. I also want to thank my DrPH peers and friends for offering the support and inspiration needed to finish this dissertation, particularly Anthony Peluso. We met at orientation and from that day on he has always been there to offer advice, encouragement, and a good laugh. From Yoakley to the Innovation Lab to Lamb Hall, we have shared this experience together and will forever be family. And to my best friend Caitlin, for always being there for me through thick and thin.

Most importantly I must thank the doctors, nurses, directors, legislators, and other professionals who took time out of their busy schedules to share their experiences with me. Without their willingness to participate in this important research, none of this would have been possible. And, last but not least, to all of the Tennesseans and their families who are faced with end-of-life healthcare choices, it is because of them that this research was not only needed, but also important. Thank you.

TABLE OF CONTENTS

ACRONYMS AND ABBREVIATIONS

AAMC	Association of American Medical Colleges
AARP	American Association of Retired Persons
APHA	American Public Health Association
ADL	Activities of Daily Living
ADRC	Aging and Disability Resource Centers
ALS	Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease)
AMA	American Medical Association
APA	American Psychological Association
ASA	American Society on Aging
CDC	Center for Disease Control
CHF	Congestive Heart Failure
CLASS	Community Living Assistance Services and Support Act
CMS	Centers for Medicare & Medicaid Services
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardiopulmonary Resuscitation
DNR	Do Not Resuscitate
DWDA	Death with Dignity Act
EHR	Electronic Health Record
EOL	End-of-Life
ER	Emergency Room
GIP	General In-Patient
GOC	Goals of Care
HB	House Bill
HCBS	Home and Community Based Services
HIPAA	Health Insurance Portability and Accountability Act
HPV	Human Papillomavirus

ICU	Intensive Care Unit
IOM	Institute of Medicine
IRB	Institutional Review Board
LTSS	Long-Term Services and Supports
MD	Medical Doctor
NCI	National Cancer Institute
NCSS	National Council for the Social Studies
NHPCO	National Hospice and Palliative Care Organization
NHS	National Health Service
NIH	National Institute of Health
PA	Physician’s Assistant
POLST	Physician Orders for Life-Sustaining Treatment
TMA	Tennessee Medical Association
VA	Veteran’s Affairs

Chapter 1. Introduction

Problem Statement

The state of Tennessee is on the cusp of what may be the biggest public health crisis in recent history; a rapidly aging population and an unprepared, and poorly rated, end-of-life healthcare system. Not since the opioid epidemic was declared a public health emergency by the Department of Health and Human Services in 2017 (HHS.gov, 2019) has the state faced an event that could significantly impact healthcare services in this magnitude. According to an article in the Chattanooga Times Free Press, Tennessee's aging population faces an uncertain future (Fite, 2017). State programs have limited capacity and minimal funds to meet the demands of the aging population. Emily Long, a research and policy analyst for the Tennessee Commission on Aging and Disability explained that the state is trying to do what is best for older adults, but with the department's small budget, caring for seniors and preparing to serve the growing population of Tennesseans over 65 are the two biggest obstacles (Fite, 2017).

In 2010, the 65 and older age group in Tennessee accounted for 13.4% of the population, and by 2016 it had increased to 15.7%. The projected percentage for the 65 and older age group in 2030 is 22% of the state population (US Census Bureau, 2017). According to Tennessee government officials, the projected growth in other age groups in the state is relatively steady, or in some cases, declining by 2030, but the five age groups over 65 are all projected to increase (tn.gov, 2019). According to retired Tennessee internist Dr. Wayne Scott, "Older physicians are bailing, and there's more and more patients with the aging of the population, and their problems are more complicated." (Fite, 2017, p. 1). This is a problem when the projected population growth does not match the college graduation rate in health care professions (Fite, 2017). With the senior population living longer, and sometimes with chronic diseases, there will be a greater demand for healthcare services that address geriatric health issues.

The current growth of the population aged 65 and older is one of the most significant demographic trends in the history of the United States, and it is impacting the entire country, not just the state of Tennessee. This unprecedented growth emphasizes the need for healthcare policy that addresses end-of-life issues (Population Reference Bureau, 2019). In 2018 there were 52 million Americans aged 65 or older. By 2030, this number is projected to increase to 71 million, about 20 percent of the population (Health and Aging Policy Fellows, 2018). Those who are 85 and older are projected to increase to 8.7 million in 2030 from 5.8 million reported in 2010 (Healy, 2013). These dramatic increases will create critical challenges for the healthcare system, social services, and national and state legislators. According to Jonathon Vespa, a U.S. Census Bureau demographer, “The aging of baby boomers means that within just a couple decades, older people are projected to outnumber children for the first time in U.S. history” (U.S. Census Newsroom, 2018).

In 1950, the average life expectancy in the United States was 68 years old, in 2017 it had increased to 78.6 years old. This increase can be attributed to a reduction in mortality rates for older adults (Population Reference Bureau, 2019). As Americans live longer lives, they will be at a higher risk for health problems that are more complex, disabilities that limit their daily activities, chronic illnesses, and comorbidities (Health and Aging Policy Fellows, 2018). The aging of the 65 and older population could cause an increase in the use of nursing home care by more than 50 percent. This would mean that the number of Americans in nursing homes could increase from 1.2 million in 2017 to 1.9 million by 2030 (Population Reference Bureau, 2019).

The population over 65 also has a declining mortality rate. This is a trend that is seen across the United States, but it is of particular concern in Tennessee due to the state's poorly rated end-of-life healthcare. In a national ranking of states according to their quality of end-of-life health care, Tennessee was ranked 47th out of the 50 states in long-term services and supports (LTSS) (American Association of Retired Persons [AARP], 2017). This ranking was given based on the following five areas of assessment: affordability and access, choice of setting and provider, quality of life and quality of care, support for family caregivers, and effective transitions (Table 1).

The Long-Term Services and Supports Scorecard uses 25 indicators across five dimensions. Affordability and access include things such as the affordability of private pay to cover LTSS, how easy it is to navigate the LTSS system, and the number of people who have private long-term insurance, among others (AARP, 2017). Choice of setting and provider uses six indicators including the availability and number of nursing home alternatives, and the quantity of personal care aides and home health workers. The third dimension is quality of life and quality of care. The three indicators include two indicators of nursing home quality and one rates the number of people with disabilities who have employment in the community (AARP, 2017).

Support for family caregivers is a single policy composite that is divided into four indicators. They include person and family centered care, delegation of nurses, support for working caregivers, and policies for transportation (AARP, 2017). The final dimension, effective transitions, uses six indicators to determine a ranking. These indicators include the measures of institutionalization and hospitalization that should be minimized in order to achieve a LTSS system that is high-performing (AARP, 2017).

Table 1

Tennessee Long-Term Services and Supports Scorecard

Affordability and Access	**Overall Rank: 43**				
	2017 Scorecard				
Dimension and Indicator	**Data Year**	**State Rate**	**All States Median**	**Best State Rank**	**Rank**
Median annual nursing home private pay coast as a percentage of median household income age 65+	2015-16	201%	233%	164%	11
Median annual home care private pay cost as a percentage of median household income age 65+	2015-16	76%	81%	46%	15
Private long-term care insurance policies in effect per 1,000 people age 40+	2015	48	48	164	24
Percent of adults age 21+ with ADL disabilities at or below 250% of poverty receiving Medicaid	2014-15	47%	53.4%	78.1%	45
Medicaid LTSS beneficiaries per 100 people with ADL disabilities	2012	25	54	111	50
ADRC/No Wrong Door Functions (composite indicator, scale 0-100%)	2016	33%	60%	92%	45
Choice of Setting and Provider	**Overall Rank: 45**				
	2017 Scorecard				
Dimension and Indicator	**Data Year**	**State Rate**	**All States Median**	**Best State Rank**	**Rank**
Percent of Medicaid and state funded LTSS spending going to HCBS for older people and adults with physical disabilities	2014	35.1	33.1	68.5	23
Percent of New Medicaid aged/disabled LTSS users first receiving services in the community	2012	27.1	55.4	83.6	50
Number of people participating-directing services per 1,000 people with disabilities	2016	2.8	9.6	131.9	41

Home health and personal care aides per 100 adults age 18+ with ADL disabilities	2013-15	13	19	41	40
Assisted living and residential care units per 1,000 population age 75+	2014	44	52	121	31
Subsidized housing opportunities (place-based and vouchers) as a percentage of all housing units	2015	5.6	5.8	17.7	30
Quality of Life and Quality of Care	**Overall Rank: 47**				
	2017 Scorecard				
Dimension and Indicator	**Data Year**	**State Rate**	**All States Median**	**Best State Rank**	**Rank**
Rate of employment for adults with ADL disabilities ages 18-64 relative to rate of employment for adults without ADL disabilities ages 18-64	2014-15	15.5%	21.9%	43.3	50
Percent of high-risk nursing home residents with pressure sores	2015-16	5.3%	5.5%	3.4%	23
Percent of long-stay nursing home residents who are receiving an antipsychotic medication	2015	20%	16.8%	8%	46
Support for Family Caregivers	**Overall Rank: 49**				
	2017 Scorecard				
Dimension and Indicator	**Data Year**	**State Rate**	**All States Median**	**Best State Rank**	**Rank**
Supporting working caregivers (composite indicator, scale 0-9.0)	2014-16	0.0	1.0	6.50	32
Person – and Family – Centered Care (composite indicator, scale 0-5.5)	2016	1.5	2.41	4.3	34
Nurse Delegation and Nurse Practitioner Scope of Practice (composite indicator, scale 0-5.0)	2016	0.5	4.0	5.9	45
Transportation Policies (composite indicator, scale 0-5.0)	2012-16	1.0	1.0	4.0	20

Effective Transitions	**Overall Rank: 23**				
	2017 Scorecard				
Dimension and Indicator	**Data Year**	**State Rate**	**All States Median**	**Best State Rank**	**Rank**
Percent of nursing home residents with low care needs	2014	6.4%	11.2%	4.1%	5
Percent of home health patients with a hospital admission	2015	24.2%	24.4%	18.3%	24
Percent of long-stay nursing home residents hospitalized within a six-month period	2014	19.4%	15.7%	5.0%	40
Percent of nursing home residents with moderate to severe dementia with one or more potentially burdensome transitions at end of life	2013	23.3%	23.8%	9.1%	25
Percent of new nursing home stays lasting 100 days or more	2012	20.8%	18.3%	8.9%	39
Percent of people with 90+ day nursing home stays successfully transitioning back to the community	2012	8.5%	7.4%	14.9%	17

On January 15, 2018, the State of Tennessee released its final report on the Palliative Care and Quality of Life Taskforce. For patients with a serious medical condition, palliative care is considered a specialized medical treatment (Tolbert, 2016). It is similar to hospice care in some ways but has several distinctions. Palliative care is an approach that is appropriate during any stage of an illness, not just at the end-of-life, with the main focus being the improvement of quality of life (Council on Aging of Middle Tennessee, 2015). The taskforce was led by Sen. William H. Frist, MD, the former U.S. Senate Majority Leader. In the opening letter of the report he wrote, “Across our state there remain significant gaps in the availability of palliative care and a shortage of trained providers” (tn.gov, 2018). This report highlights the inadequacies in Tennessee’s end-of-life healthcare, affirming the national ranking given.

Unlike some public health crises that occur, or are predicted to occur, the aging of the U.S. population is not something that can be avoided or stopped, but it can be prepared for. Some areas of healthcare that need to be addressed to prepare for this demographic shift in the country's population include: enhanced regulation of long-term care facilities and nursing homes, an increase in the amount and regulation of in-patient hospice facilities, strategies to improve chronic care coordination, and funding for training health professionals in applicable fields (Health and Aging Policy Fellows, 2018).

In September of 2014, The Institute of Medicine (IOM) released *Dying in America: Improving quality and honoring individual preferences near the end of life*. This was the IOM's fifth full report on end-of-life issues since the first report in 1997, but this was the first time the Institute explicitly addressed the role of public health in this area of healthcare (Ness, 2015). In a policy brief of the 2014 report, the five areas of end-of-life care that need improvement are discussed, as well as recommendations for making the changes needed (Meghani, 2015). These five areas are:

- Delivery of care: The IOM describes current end-of-life care in the United States as "fragmented", with rates of highly preventable hospitalizations, and transitions between care settings that are poorly managed.
- Clinician-Patient Communication and Advanced Care Planning: The IOM states that there is a lack of patient-clinician conversations regarding end-of-life planning and other issues, and that quality standards need to be developed.
- Professional Education and Development: There needs to be a strengthening of the training and certification requirements of health care professionals who care for people

who are near the end of life. Currently, there is insufficient attention given to this area of health care in medical and nursing schools.

- Policies and Payment Systems: The lack of end-of-life policy and planning leads to the overuse of emergency rooms and the 911 system. This is due to the lack of availability to coordinated care such as hospice or palliative care. There is also an issue of payment policies that discourage coordination among providers.
- Public Education and Engagement: The 1997 IOM report called for an improvement in understanding the modern dying experience, and according to the latest report, this has still not happened. The committee reports that most Americans are unaware of their end-of-life options, do not discuss death and dying with their family or doctors, and are not prepared for end-of-life care when needed.

According to an article published in The Tennessean, a Nashville newspaper, senior health in the Tennessee ranks “among the worst in the country” (Fletcher, 2015). A study conducted by United Health Foundation based this ranking on the state having a shortage of geriatric physicians, fewer home health workers per 1,000 people, and high levels of inactivity among the senior population (United health Foundation, 2015). This ranking is just one of several where the state of Tennessee ranks poorly in the area of end-of-life healthcare. Combining this with the state’s rapidly growing senior population creates an environment for a public health crisis which can have significant impacts on human life, community health, and on the economy, and it can be the result of industry, disease, or poor policy. Some prevalent social problems not specifically related to traditional notions of disease -- or formerly referred to as such -- become recognized as public health crises once they reach saturation point. Tennessee is reaching that point.

Conceptual Model

Improving end-of-life healthcare in Tennessee will require the participation and support of many stakeholders. These include the general population of Tennessee, healthcare professionals, medical organizations, advocacy groups, and most importantly Tennessee policy makers. One conceptual framework that has been used in the area of policy implementation and dissemination is the Multiple-Streams Framework (Figure 1) (Kingdon, 2014). This approach was developed in 1984 by John Kingdon and will be used as the analytic design of this research (Figure 1) (Kingdon, 2014).

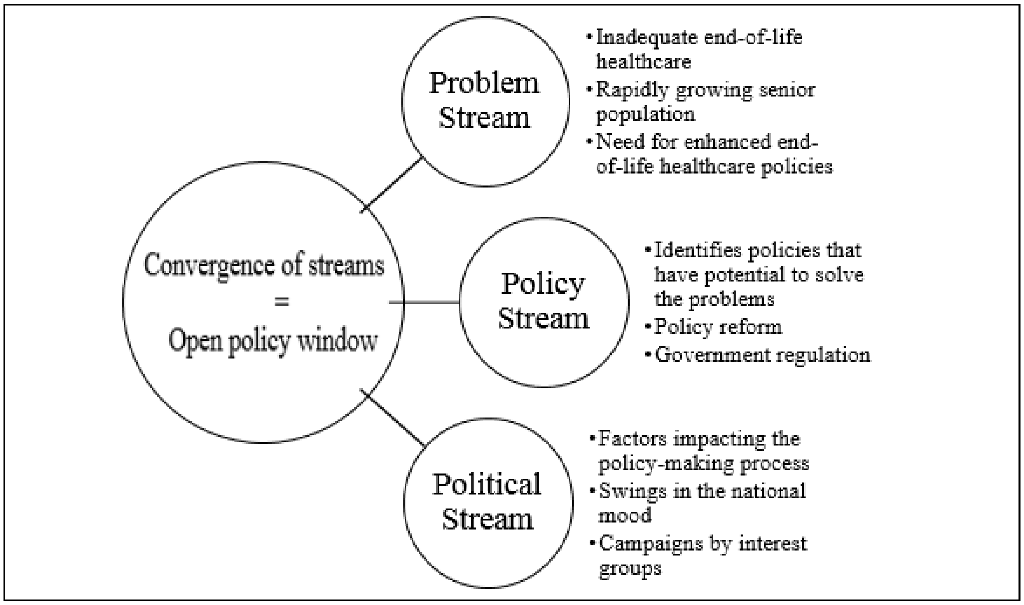
The Multiple-Streams Framework focuses on three categories of independent, and sometimes interdependent, variables. These three variables interact to produce, what Kingdon refers to as, "windows of opportunity" for policy change (Beland, 2016). The first construct is the "Problem Stream". This is where health problems are identified, and issues are framed, and can sometimes be identified as a result of a crisis or an event that attracts public attention (Kingdon, 2014). In other words, it is the definition of the problem. For this research, the definition of the problem is that due to inadequate end-of-life healthcare and a rapidly growing senior population, there is a need to assess legislative concern and political will to enhance end-of-life healthcare policies and programs in the state.

The second construct is the "Policy Stream" which identifies policies that have the potential to solve the problem a population is experiencing. This can also include conditions that need government intervention, or policies already in place that need to be reformed (Kingdon, 2014). Both the first and second streams are concerned with how certain problems or conditions can become important or critical enough to impact the government's intervention with policy. The third construct is the "Political Stream" which identifies what factors are impacting the policy making process (Brownson, 2012). This can include swings in the national mood, executive change, legislative turnover, and campaigns by interest groups (Beland, 2016).

For end-of-life healthcare policy to change in the state of Tennessee, these three "streams" will have to converge. According to Kingdon, the channels travel separately and remain for the most part independent of each other until, at a specific point in time, a window opens for policy enactment or reform. It is only then that the streams cross (Kingdon, 2014). It is because of this that it is of the utmost importance that public health policies not only be technically well-written, but also politically feasible. As end-of-life legislation continues to expand to more and more states across the country, the state of Tennessee and the legislators who navigate policy implementation and reform, must address this critical area of healthcare. More importantly, they must assess the status of the states' current end-of-of-life healthcare and the steps that must be taken to improve it.

Figure 1

Multiple-Streams Framework



Research Aims

Currently there is limited literature about the motivating factors that influence policy makers' voting decisions and policy change initiatives in any area, including end-of-life healthcare. This research will be one of only a few studies that has explored what motivates and influences policy makers. Other stakeholders including state department directors, healthcare professionals, advocacy organization employees, and former legislators will also be included to learn what influences their participation in end-of life healthcare issues.

Aim 1: Examine the motivation of key decision makers behind participation in departments of the Tennessee State Government that focus on end-of-life healthcare, non-profit organizations, for-profit organizations, advocacy groups that focus on any aspect of end-of-life healthcare in Tennessee, and former legislators who proposed end-of-life healthcare legislation in Tennessee while an elected official.

Objectives:

- Identify the motivating factors that influence the decision to work in state departments and healthcare organizations that focus on end-of-life healthcare.
- Assess whether motivating factors of involvement are personal, ethical, economical, faith-based, based on personal experience, or other.

Aim 2: Critically assess the decision-making process that key decision makers in departments of the Tennessee State Government that focus on end-of-life healthcare, non-profit organizations, for-profit organizations, advocacy groups that focus on any aspect of end-of-life healthcare in Tennessee, and former legislators who proposed end-of-life healthcare legislation in Tennessee while an elected official employ, specifically when it applies to end-of-life healthcare.

Objectives:

- Identify what factors impact the decision-making process, including swings in the national mood, executive change, and campaigns by interest groups.
- Classify what each stakeholder considers end-of-life healthcare.
- Assess whether improving end-of-life healthcare in Tennessee is a priority.
- Assess whether preparing for the rapidly aging population in Tennessee is a priority.

Aim 3: Measure the support among key decision makers in departments of the Tennessee State Government that focus on end-of-life healthcare, non-profit organizations, for-profit organizations, advocacy groups that focus on any aspect of end-of-life healthcare in Tennessee, and former legislators who proposed end-of-life healthcare legislation in Tennessee while an elected official for end-of-life healthcare policy that would improve quality of care and expand options for terminally ill Tennesseans.

Objectives:

- Determine the individual perceived quality of Tennessee’s end-of-life quality level and how improving end-of-life healthcare in Tennessee can become a reality.
- Assess the support for end-of-life care policy, including a Tennessee Death with Dignity Act, and the influences on that support or lack thereof.
- Identify the barriers to improving end-of-life healthcare in Tennessee, and who or what is causing them.

Aim 4 (Informed by Aims 1, 2, and 3): Critically assess the policy-making process that current Tennessee state legislators employ, specifically, when it applies to end-of-life healthcare policy.

Objectives:

- Identify what factors impact the policy making process, including swings in the national mood, executive change, legislative turnover, and campaigns by interest groups.

- Assess whether motivating factors of policy decisions are personal, ethical, economical, faith-based, based on personal experience, or other.
- To determine how certain problems or conditions can become important or critical enough to impact the government's intervention with policy.
- Classify what each legislator considers end-of-life healthcare.
- Assess whether improving end-of-life healthcare in Tennessee is a priority.
- Assess whether preparing for the rapidly aging population in Tennessee is a priority.

Aim 5 (Informed by Aims 1, 2, and 3): Measure the support that current state legislators have for end-of-life healthcare policy that would improve quality of care and expand options for terminally ill Tennesseans.

Objectives:

- Determine the individual perceived quality of Tennessee's end-of-life quality level and how improving end-of-life healthcare in Tennessee can become a reality.
- Develop steps to implementing policy change in the area of end-of-life healthcare and expanding options for terminally ill individuals.
- Assess the support for end-of-life care practices, including a Tennessee Death with Dignity Act, and the influences on that support or lack thereof.
- Identify the barriers to improving end-of-life healthcare in Tennessee, and who or what is causing them.

Significance

It is anticipated that the knowledge gained from this research will lead to the enactment of end-of-life healthcare policy in Tennessee. The state will see improvements in all aspects of end-of-life healthcare, specifically in the areas of affordability, access to hospice and palliative care, choice of setting, choice of provider, quality of life, quality of care, and support for family caregivers. Other improvements could include increased communication between patient and provider, mandatory professional development and education in end-of-life healthcare decision making for medical professionals, increased use of advance directives, and eventually expanded choices in end-of-life healthcare including physician-assisted death.

The outcome objective of this research is to learn what inspires policy enactment, motivates policy makers and other stakeholders, what is considered end-of-life healthcare and the individual assessment of its quality level, and how improving end-of-life healthcare in Tennessee can become a reality. It is also an objective to learn if improved end-of-life healthcare for the rapidly aging population can eventually lead to an End-of-Life Care Act which will expand choices for all terminally ill Tennesseans.

There is very little existing literature about the individual motivating factors that influence policy makers' voting decisions and policy change initiatives. This research will be one of only a few studies that has explored this very important topic. Whether or not policy makers are motivated by political outcomes, reelection, peer acceptance, or by personal values, among others, will all be explored through this research to alter the future of how policy is introduced, passed, and enacted in the state of Tennessee. Other stakeholders including state department directors, healthcare professionals, as well as advocacy organization employees will also be included to learn what influences their participation in end-of life policy change initiatives and advocacy. All participants will inform this research about what end-of-life healthcare in Tennessee means to them and what needs to be done to ensure its improvement to meet the challenges ahead.

This study will use qualitative methods to measure the aims and objectives of this research. By using semi-structured interviews on a one-to-one level, aims will be addressed using a method that will ensure a high level of validity. Results in this study will be significant in learning more about the future of end-of-life healthcare policy in Tennessee.

Chapter 2. Literature Review

End-of-Life Healthcare

End-of-life healthcare has been described as “the support and medical care given near death, whether from a sudden illness, a life-ending disease or old age” (Council on Aging of Middle Tennessee, 2015, p. 6). Care could be received in the final days, weeks, months, or even years, though that is rare. Medical care is given whether the dying person’s condition is curable or terminal and can be done in palliative or hospice care (Fay, 2018). End-of-life healthcare is typically paid for by private insurance, Medicare, Medicaid, charities, the individual, or family. (Fay, 2018). Settings where care is provided generally varies and is greatly dependent on the resources that are available, the patient’s goals of care, and the level of care that is required (Bernazzani, 2016). The three major facilities that provide end-of-life care are hospitals, nursing homes, and the patient’s home (Fay, 2018), though residential hospice facilities can sometimes be the preferred location when available.

In the United States, efficient and regulated end-of-life care is becoming more essential as the overall population increases, and life expectancy is extended. In the Center for Disease Control and Prevention’s 2016 Health Report, the number of deaths in the United States in 2015 was 2,712,630, a rate of 844.0 per 100,000. This number was an increase of 86,212 more deaths than in 2014 (CDC, 2016). In 2017 deaths in the United States increased to 2,813,503, a rate of 863.8 per 100,000, and will continue to increase annually (CDC, 2019). According to the co-chair of the Institute of Medicine’s Dying in America committee, Phillip A. Pizzo, the United States is “at a cusp in history when longevity is changing the demography of the world. This too impacts the number of individuals who will face end-of-life issues” (Pizzo, 2016, p. 12,909). Unfortunately, there are many Americans, old and young, who will die from chronic illnesses that include a gradual deterioration with physical, social, spiritual, and emotional pain (Wasserman, 2007).

According to an article published in the Annals of Medicine, “There may be no truer test of a health care system than how it supports persons with advanced illness or at the end of life, and the loved ones who care for them. In that regard, most would agree that our health care system struggles and often fails” (Rao, 2015, p. 230). Not only does this failure cause both physical and emotional suffering, but it also adds a financial burden to the families involved (Rao, 2015). The National Hospice and Palliative Care Organization’s former President and CEO, J. Donald Schumacher explained that in the United States it can be very hard for patients to receive good end-of-life care because the goal of medicine is to keep treating people for their health problems and doctors struggle to have the necessary conversations (Clift, 2011). This can be problematic when there is no hope for a cure and the goal is to keep people alive regardless of the emotional, physical, or financial costs. This sentiment is addressed in an article written by the editor of the British Medical Journal, who states “If death is seen as a failure rather than an important part of life, then individuals are diverted from preparing for it and medicine does not give the attention it should to helping people die a good death” (Smith, 2000, p. 129).

According to the Council on Aging of Middle Tennessee there are five concepts that inform end-of-life decision making: comfort, companionship, closure, control, and cost (Council on Aging of Middle Tennessee, 2015). These concepts can vary in their importance and substance, so it is recommended that individuals examine their own personal thoughts, values, and feelings regarding their medical decisions and care (Council on Aging of Middle Tennessee, 2015). Studies show that 90% of Americans agree that discussing plans, values, and preferences for end-of-life healthcare is important, but only 27 percent actually do (Holly, 2019). In 2018, The Journal of the American Medical Association published a forum titled “End-of-Life Care, Not End-of-Life Spending”. According to the author, “Emerging evidence suggests that saving money on end-of-life care is much easier said than done. Instead of focusing on spending, we should focus on improving the well-being of those who are terminally ill” (Jha, 2018, p. 631). In the United States, a significant amount of money is spent at the end of life. In fact, one-fourth of all Medicare spending is spent on healthcare during the last year of life. However, the problem is not as much about wasteful spending, but more about poor end-of-life healthcare (Jha, 2018, p. 631).

Hospice

Hospice organizations began as nonprofit entities and remained that way for a long time (Jaffe, 2017). The first hospice was established in a residential suburb of London in 1967 by an Anglican nurse named Cicely Saunders (Hallman, 2014). She explained that the final stages of life should be seen as a fulfillment and not as a defeat. The hospice “movement” began in the United States in 1982 after Congress passed the Medicare hospice benefit. It was at this point that hospice became more of a for profit establishment than a charitable one in this country (Hallman, 2014).

According to the National Hospice and Palliative Care Association, the principal objective of hospice is to focus on enhancing the quality of life a person has left and to make them as comfortable as possible (nhpco.org, 2014). It exists so that people whom doctors have determined have six months or less left to live can be provided comfort (Hallman, 2014). The Council on Aging of Middle Tennessee expands that definition beyond providing comfort, to include maximizing quality of life, ensuring symptom relief, supportive comfort care, and assisting family with important end of life issues (Council on Aging of Middle Tennessee, 2015).

Hospice care is typically given in a team-centered approach. Team members can include nurses, doctors, social workers, spiritual leaders, psychologists, pharmacists, volunteers, and others (Fay, 2018). It can be given at a number of places including assisted living facilities, hospitals, hospice centers, nursing homes, or at home (Fay, 2018). Hospice centers, or residential hospice facilities, are needed when family members are unable to do the majority of care at home on the days when hospice workers do not visit. In 2017 1.1 million Medicare beneficiaries who died were enrolled in hospice. Of these deaths, 48.2% occurred in the home, 31.8% in nursing home facilities, 11.2% were in residential in-patient hospice facilities, 7% in hospitals, and 1.7% were categorized as "other" (National Hospice and Palliative Care Organization, 2019).

The state of Tennessee has an alarmingly small number of residential hospice facilities. There are only six facilities with a total of 108 beds to accommodate all 95 counties in the state (healthtn.gov, 2019). This is a reduction in facilities from 2017, when there were eight facilities with a total of 148 beds (healthtn.gov, 2017). These facilities are important to individuals who may not have family members to keep them in hospice at home, and with a rapidly growing senior population, the low number of residential hospice facilities is a major concern.

Palliative Care

Palliative care is considered a specialized medical treatment for patients with serious illnesses (Tolbert, 2016). Though very similar to hospice care, palliative care has several distinct differences. It is a treatment approach that is appropriate during any stage of an illness, not just at the end-of-life. The main focus of palliative care is to "improve the quality of life for people facing serious or chronic illness. It concentrates on pain and symptom management, communication, and coordination of the patient's care" (Council on Aging of Middle Tennessee, 2015, p. 7). It is given as a supplement to treatment and can make life more comfortable for people living with a chronic illness. Hospice and palliative care both aim to relieve suffering and improve quality of life, however palliative care does not require a prediction of six months or less left to live and curative treatments can continue (Council on Aging of Middle Tennessee, 2015).

Like hospice, palliative care employs a multidisciplinary approach to care. This team provides medical, emotional, social, and practical support (National Institute on Aging, 2017). Palliative care teams are composed of clinicians from different disciplines who work in varying fields. They can act as a link between ambulatory, community, and in-patient settings (Tuggey & Lewin, 2014). Another similarity is that it can be provided in varying locations such as hospitals, outpatient palliative care clinics, nursing homes, other specialized clinics, or at home. Payment options also include Medicare, Medicaid, private insurance, and self-pay (National Institute on Aging, 2017). Palliative care starts when a person is diagnosed and continues until the patient recovers or when they are determined to have less than six months to live. At that point they would switch to hospice care (Fay, 2018).

The Center to Advance Palliative Care at the National Palliative Care Research Center released “America’s Care of Serious Illness” in 2015. It was a state-by-state report card on access to palliative care in American hospitals. In the introduction, the authors stress the importance of palliative care being used to treat the patient as a whole person (Center to Advance Palliative Care, 2015). They explain, “Palliative care teams begin by learning about a patient’s priorities, symptoms, and other problems-perhaps social, emotional, or spiritual-and then work to ensure that the care they provide is aligned and coordinated with the needs of that patient as a whole person”. This is done by determining patients’ goals of care through communication that is skilled (Center to Advance Palliative Care, 2015, p. 4)).

In the 2015 State-by-State Report Card it is shown that millions of Americans have inadequate access to palliative care. These Americans are living with serious illness such as heart disease, dementia, cancer, and kidney disease (Center to Advance Palliative Care, 2015). Even hospitals that report having palliative care teams are often unable to see every patient in the hospital who could benefit from their services because they are stretched too thin. This is one of the reasons that a third of the states in the country received a grade of C or D in palliative care ratings (Center to Advance Palliative Care, 2015). Grades were based on the percentage, of each individual state, of the prevalence of palliative care teams in hospitals with more than 50 beds. Tennessee received an overall ranking of 56 out of 100, which was considered a C. The East South-Central Region which included Tennessee, Alabama, Kentucky, and Mississippi ranked as the lowest in the country (Center to Advance Palliative Care, 2015).

Establishing End-of-Life Directives

Advance care plans can benefit all people, no matter their age or health status. Illness and accidents can happen at any time, so having end-of-life preferences specified ahead of time can benefit individuals and their family. Typically, older adults or adults facing a life-threatening illness are more likely to have an advance care plan or advance directive, but it is important for everyone (Tolbert, 2016). The state of Tennessee has specific guidelines set forth in "Advance Directives for Health Care Decision Making" where it is explained that advance care plans can help individuals communicate the choices they want for treatment if they were otherwise unable to make their own decisions (TN.gov, 2019). Some of the situations that can be addressed with an advance care plan are that an individual can specify if they would want cardiopulmonary resuscitation (CPR) or if they want to be a DNR (do not resuscitate). The decision to have kidney dialysis or breathing machines as well as other special instructions or limitations that honor your values can also be included (TN.gov, 2019).

Prior to 2004, the term for an “Advance Care Plan” in Tennessee was “Living Will”. Another term that was legally changed in Tennessee’s new law in 2004 was “Medical Power of Attorney”. That term is now referred to as an “Appointment of Health Care Agent”. An Appointment of Health Care Agent is a type of advance directive that allows a person to legally appoint a person to make their health care decisions if they are unable to do so for themselves (End of Life Care Tennessee, 2019). The difference between the two is that an advance care plan is an individual’s written instructions for their preference, and the appointment of a health care agent is the assignment of a third party to make health care decisions for that person (End of Life Care Tennessee, 2019).

Advance Directives refer to the legal documents that enable an individual to convey their decisions regarding end-of-life healthcare. These documents include: Advance Care Plans/Living Wills, DNR/POLST orders, Appointment of Health Care Agent/Durable Power of Attorney for health Care, or any other legal document which defines an individual’s end-of-life healthcare preferences (Council on Aging of Middle Tennessee, 2015). Adults over the age of 18 and any emancipated minor who have mental capacity to make decisions for themselves can create an advance directive. No lawyer is necessary to create an advance directive, but it must be witnessed by two adults with mental capacity and then notarized when signed (End of Life Care Tennessee, 2019). Even though the process for creating standardized advance directive forms was necessary, creating individual directives is a highly personalized process. It involves engaging each person and his or her family in a unique and intimate process, and it is beneficial to include the individual’s physician, other caregivers, and depending on the individual, spiritual advisor.

Ethical Concerns Around End-of-Life Healthcare

According to the Council on Aging of Greater Nashville, “People often have serious concerns about ethical or moral issues involved with providing care at the end of life”. One of these concerns is considering the use of artificial nutrition and hydration (Council on Aging of Middle Tennessee, 2015, p. 10). Near the end of life people sometimes lose the ability or desire to swallow liquids or solid food. There may also be the loss of an individual’s ability to absorb nutrients from food due to their illness. It is during these situations that the use of a feeding tube may be discussed. Some may argue that withholding a feeding tube will result in starvation, while others argue that force feeding an individual goes against letting nature take its course (Council on Aging of Middle Tennessee, 2015).

Another area of concern is whether or not to perform CPR when nearing the end of life. CPR has been given unrealistic expectations of always being successful by the way it is portrayed in television shows and movies. In reality, in healthy individuals it is only successful 70 percent of the time. In patients over 60 years old, CPR is only successful 22 percent of the time. That number drops to 10 percent when an individual over 60 years old has a late stage illness (Council on Aging of Middle Tennessee, 2015). In addition to CPR, another area of concern in end-of-life healthcare is the use of a ventilator. When faced with a life-limiting, or terminal condition, it is in the patient’s best interest to decide his or her preference for the use of a ventilator and have it expressed in an advance care plan (Council on Aging in Middle Tennessee, 2015).

The most highly controversial area of end-of-life healthcare in the United States is physician-assisted death, but support for its legalization is growing as more states have legalized the practice (Sulmasy & Mueller, 2017). Over the last five years the legal landscape for physician-assisted death has changed dramatically, with over 20% of the population in the United States now living in a state where aid-in-dying is legal (Buchbinder, et al., 2019). The state of Oregon first passed a law to legalize physician-assisted death in 1994, and it was enacted three years later in 1997 (Regan & Alderson, 2003). It was the first law in the United States to give terminally ill people the option to obtain access to legalized physician-assisted death (Ganzini et al. 2009). According to Oregon's Public Health Division, physician-assisted death allows terminally ill adult Oregonians to obtain and use prescriptions from their physician for self-administered, lethal doses of medications (Oregon Public Health, 2019).

Though not every medical association has publicly endorsed physician-assisted death, many have, including the American Public Health Association. In 2008, eleven years after the enactment of Oregon's Death with Dignity Act, the American Public Health Association (APHA) officially endorsed physician-assisted death as a generalizable public health policy titled "Patients' Rights to Self-Determination at the End of Life" (Allison, 2010). In this policy statement, the APHA referred to Oregon's Death with Dignity Act as "The Oregon Model" and publicly supported "allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place, and manner of his or her impending death where safeguards equivalent to those in the Oregon DWDA (Death with Dignity Act) are in place" (APHA, 2008, p. 3). Since then, Washington, Vermont, California, Colorado, Washington D.C., Hawaii, New Jersey, and Maine have each passed similar Acts (Compassion and Choices, 2020).

End-of-Life Healthcare Benefits from Having a Death with Dignity Act

Research shows that there have been numerous benefits for residents of Oregon in the area of end-of-life health care because of the Death with Dignity Act (DWDA). According to a study in the New England Journal of Medicine, Oregon is a leader in excellent palliative care. They have a high number of hospice referrals, along with the public awareness of end-of-life options (Quill, 2004). In fact, the Oregon Public Health Department reported in its 2016 statistics on the Death with Dignity Act, that 88.7% of participants were enrolled in hospice at the time of their death (Oregon Public Health, 2017). Washington State's Public Health Department's 2016 statistics reported that 88% of its Death with Dignity Act participants were in hospice as well (Washington Public Health, 2017). Data support the idea that legalizing physician-assisted death can improve palliative and hospice care, not diminish it. According to the American Public Health Association, physicians in Oregon "are more comfortable discussing end-of-life issues with their patients since the enactment of the Death with Dignity Act, which focused attention on end-of-life care and the options available to individuals" (APHA.org, 2008, p. 2).

In an article published in the New England Journal of Medicine, end-of-life healthcare in Oregon is highlighted due to the state's ability to handle complex end-of-life healthcare issues. Key interventions and effects on patient care including the education of healthcare professionals are discussed (Tolle, 2017). A high percentage of physicians and other healthcare professionals in Oregon, including hospice nurses, receive end-of-life training courses. According to Dr. Timothy Quill, an American physician specializing in palliative care and an expert in legalized assisted dying, "Overall, Oregon appears to be among the leaders in comparison to other states in virtually all aspects of palliative and end-of-life care, including allowing open access to physician-assisted death, subject to safeguards" (Quill, 2008, p. 20). When Oregon enacted the

Death with Dignity Act in 1997, “It established a civil, criminal, and disciplinary safe harbor for physicians and others who followed its eligibility criteria and procedural protocol” (Coombs-Lee, 2014, p. 94). In addition to the terminally ill participants, many healthy Oregonians find it psychologically reassuring to have the option to access the Death with Dignity Act if they ever need it (Orfali, 2011).

History of Proposed Tennessee Death with Dignity Acts

On March 31, 2015, Rep. Craig Fitzhugh (D-Ripley) introduced HB 1040 with two co-sponsors, Rep. David Alexander (R-Moore) and Rep. Judd Matheny (R-Coffee) (Tennessee.gov, 2016). This bill was named the Tennessee Death with Dignity Act, and it was the first time in the history of the Tennessee legislature that assisted-dying legislation was considered. John J. Hooker, a Tennessee resident and prominent Nashville attorney who was diagnosed with terminal cancer in January 2015, was the advocate behind this legislation. He sued the state of Tennessee for the right to end his own life with a prescription from a doctor. In a statement to the Tennessean, a Nashville newspaper, Hooker explained that he wanted Tennesseans to have the right to choose how they die, and he wanted that to be the legacy he left. Rep. Fitzhugh has said that even though he had doubts about the law on a personal level, his fight on behalf of civil rights surmounted his personal feelings (Daniels, 2015). On January 24, 2016 John Jay Hooker lost his battle with cancer, months after a court declined to hear his case in November of 2015.

The Tennessee Death with Dignity Act was moved to summer study by the House Subcommittee that considered it in 2016. Senator Reginald Tate (D-Shelby) sponsored the companion bill, SB 1362, and a hearing was held on June 9, 2016. The bills remained on file for the 2016 session, but neither one moved forward. In 2017, Tennessee State Rep. Tim Wirgau (R-Paris) sponsored HB 1394, an assisted dying bill, which he withdrew from committee a week later. Tennessee State Senator Reginald Tate (D-Shelby) introduced S 1378, a second right-to-die bill the same day, but it never progressed. There is currently no active assisted-dying legislation being considered in Tennessee (deathwithdignity.org, 2019).

End-of-Life Healthcare Policy in Tennessee

Public policy debates continue regarding issues surrounding end-of-life healthcare (Tennessee End-of-Life Partnership, 2019). The timing, opportunity, and demand to expand end-of-life healthcare are unprecedented as the population of aging Tennesseans continues to rise (Center to Advance Palliative Care, 2015). End-of-Life policy reform in Tennessee could include reimbursement to physicians, nurses, and social workers for having discussion with patients about end-of-life care or using the rate of advance directive completions as a metric of quality care. Policy could also be made to mandate end-of-life care and the use of advance directives as part of medical training, and to implement an electronic registry for advance directives (Morhaim & Pollack, 2013).

According to Health and Aging Policy Fellows, “Over the next 30 years, as the number of older Americans doubles, almost every medical specialty will have an increasingly older patient base. As a result, society is facing critical challenges regarding health and social services” (Health and Aging Policy Fellows, 2018, p. 1). National and state level decision makers are currently confronting challenges in end-of-life healthcare that span an enormous range. These challenges include restructuring end-of-life healthcare delivery, hospice facility function, the number of hospice facilities, reauthorizing the Older Americans Act, setting priorities in behavioral research in aging, access to palliative care, and expanded medical training in the area of death and dying (Health and Aging Policy Fellows, 2018). “Lawmaker interest in promoting access to palliative care is growing. Widely supported legislation pending in Congress would facilitate research, professional development, and public education in palliative care. In addition, numerous state governments are developing new initiatives and passing supportive legislation" (Center to Advance Palliative Care, 2015, p. 15).

Tennessee is facing a demographic shift over the next ten years. As the aging population increases, and longevity becomes the rule and not the exception, having adequate end-of-life healthcare is not something that can be postponed or ignored (Fletcher, 2015). Nationally recognized and respected medical associations are endorsing and promoting end-of-life care acts, and it is solidifying the need for policy across the United States. Tennessee must address the inadequacies in its current state of healthcare for the elderly, terminally ill, and increasing population over 65 years old.

Chapter 3. Research Methods

Introduction

The purpose of this research was to examine the perceived quality of end-of-life healthcare in Tennessee, including the strengths, weaknesses, and areas for improvement. It also measured the support for end-of-life healthcare policy that would improve quality of care and expand options for terminally ill Tennesseans while critically assessing the policy-making process that Tennessee state legislators employ. This exploratory research used a qualitative study design to determine how end-of-life healthcare could be improved in Tennessee and how problems, policy, and politics come together to advance change. In this chapter, the design, sampling procedures, and the methodology used to analyze the date will be explained.

Methodology

To obtain broader results from this research, a multiple methods approach was used. This approach is often referred to as a mixed methods approach or triangulation (Tolley, 2016). As part of the inductive approach, semi-structured in-depth interviews, and secondary data analysis, including relevant archived legal and political materials from the state of Tennessee and any additional organizational documentation that was relevant to the research. Institutional Review Board (IRB) approval was obtained for this project before any data collection commenced; the IRB application was approved on October 9, 2019. In order to obtain the data necessary for this topic of research, data collection was conducted in the state of Tennessee in varying locations across multiple counties and cities including Johnson City, Kingsport, Nashville, and Thompson’s Station. Additional interviews were completed via telephone and online, using video conferencing. All data were collected between October 15, 2019 and April 23, 2020.

To obtain primary data, 19 personal in-depth, semi-structured interviews using an open interview guide were conducted (Lofland, 1971). These interviews were organized in a two-tiered format, with 10 interviews being completed not only to gather data, but to inform subsequent interviews. The second tier of interviews included nine participants with an amended interview guide. Semi-structured, in-depth interviews are generally between one respondent and one interviewer and are sometimes referred to as a "conversational partnership" (Rubin & Rubin, 1995, p. 10) or a "conversation with a purpose" (Burgess, 2016, P. 102). These terms highlight the fact that in-depth, semi-structured interviews are more like a conversation between two people than the standard survey interview.

Research Design and Sampling

For the qualitative research design, the non-probability sampling technique of purposive sampling was used. This method, rather than probabilistic sampling methods, required me to draw on theory, use subjective judgements, and rely on experience in qualitative research methods to select the sample of participants (Lund Research, 2019). Unlike researchers who use probability sampling, the goal was not to necessarily achieve objectivity, or attempt to generalize to the wider population. This qualitative research design was conducted because I was interested in the intricacies of the population studied. Generalizing to the population may have been ideal, but for this research it was a secondary consideration. Understanding the processes and possibilities of end-of-life healthcare in Tennessee was the primary consideration.

Purposive sampling allowed me to comprise the study population based on specific attributes. It was designed to subjectively represent groups of stakeholders equally (Vanderstoep & Johnston, 2009, p. 187), even though they are not equally represented in the Tennessee state legislature, across State departments, or other organizations that focus on end-of-life healthcare.

This form of non-probability sampling is particularly useful in exploratory research where the aim is to let the data "speak" to you, and not force preconceived ideas to fit a theory (Vanderstoep & Johnston, 2009, p. 168).

Population of Interest

The population of interest included the Tennessee House of Representatives, the Tennessee Senate, departments of the Tennessee State Government that focus on end-of-life healthcare, and stakeholders from various hospital systems across the state including medical doctors and other practitioners with an interest in end-of-life healthcare. These stakeholders were sampled from both non-profit and for-profit organizations in Tennessee.

Tier 1 – The Experts

The Tier 1 experts (n=10) included hospice and palliative care doctors, geriatric doctors, nurses, nurse practitioners, end-of-life healthcare entrepreneurs, state government directors, and other healthcare providers with an interest in end-of-life healthcare. These experts were employed by entities including West Cancer Center Memphis, the University of Tennessee's Memphis College of Medicine, Wellmont Hospice and Palliative Medicine, East Tennessee State's Quillen College of Medicine, the Tennessee Commission on Aging and Disability, Vanderbilt University Medical Center, Alive Hospice, Avalon Hospice, and the James H. Quillen VA Medical Center. Experts were also members of several statewide advisory boards including the State Palliative Care and Quality of Life Advisory Council. The Tier 1 participants were labeled as the experts because they are all considered experts in their respective fields.

Tier 2 – The Legislators

The Tier 2 legislators (n=9) were made up of members from the health committees of the Tennessee House of Representatives (n=5) and the Tennessee Senate (n=4). The health committee of the House of Representative has 23 members, of which six are democrats and 17 are republicans. The Senate health committee has nine members, of which one is a democrat and eight are republicans (capitol.tn.gov, 2020). It is because of these small numbers that I will not be disclosing which committee and party the participants were selected from. This could violate confidentiality.

Participant Recruitment

Tier 1 – The Experts

An email, approved by the Institutional Review Board (IRB) at ETSU, was sent initially to potential Tier 1 participants selected from statewide end-of-life healthcare advisory boards. The email contained detailed information about the study and how they could participate. To reduce burden on the participants, they were advised in the email that the interview could be done at a location most convenient to them (Appendix A). There was no financial compensation for participation. Participants who were willing to participate were provided with two ways to contact me, via email or telephone. Several of the participants were contacted through their direct email that was publicly provided. Other participants were initially contacted through LinkedIn (LinkedIn, 2019). I had not anticipated this avenue for contacting potential participants, but it was a valuable resource for making contact with otherwise unreachable participants. Snowball sampling was a technique used to recruit two participants. Two of the earlier interviewees provided recommendations and contact information for experts they felt would be excellent sources for this study. Both of the recommended experts elected to participate in the study.

Tier 2 – The Legislators

After completing the Tier 1 interviews, an IRB approved email was sent to all nine members of the Tennessee Senate health committee and all 23 members of the Tennessee House of Representatives health committee. A list of all eligible participants was developed using information provided on the Tennessee General Assembly website. This list included each legislator’s name, email address, phone number, district, and party affiliation. The email contained detailed information about the study and how they could participate. To reduce burden on the legislators, they were advised in the email that the interview could be done at a location most convenient to them (Appendix B). Of the 32 original emails sent to all members of the health committees, 16 received a follow-up email after one week, and four received a third email after two weeks. Of the legislators contacted, 13 agreed to participate and scheduled interviews, but ultimately only nine were able to participate in the study.

Interview Guides

Two interview guides were used for this research. Open-ended questions were employed to allow participants to provide full and detailed responses about their experiences. Some benefits of open-ended questions include that they bring about an unlimited number of possible answers, they allow participants to answer in detail and clarify responses, and unanticipated ideas can be discovered. They also allow for more comprehensive answers to complex questions, give richness of detail, and can reveal a respondent’s thinking process and belief system. The Tier 1 interview guide was developed first since that tier was completed prior to beginning the Tier 2 interviews. After the Tier 1 interviews were completed and reviewed, the Tier 2 interview guide was edited to reflect what was learned from the experts.

Tier 1 Interview Guide

The first interview guide was for the Tier-1 participants who included hospice and palliative care doctors, geriatric doctors, nurses, nurse practitioners, end-of-life healthcare entrepreneurs, state government directors, and other healthcare providers with an interest in end-of-life healthcare. The interview guide consisted of 16 questions (Appendix C). Answers to these questions did deviate from the specific order listed on the guide at times, depending on answers given by participants. There were also discussions prompted by answers given by participants that I felt were important to pursue.

Tier 2 Interview Guide

The Tier-2 interview guide was used with Tennessee legislators who are members of the health committees of the Senate and the House of Representatives (Appendix D). This interview guide was shorter than the Tier 1 guide, in that it consisted of only nine questions. This was due in part to the fact that the Tier 2 interviews were limited to fifteen minutes.

Interview Procedures

Tier 1 Interview Procedures

Interviews were scheduled in two different ways, through email or by telephone. The majority of the participants in Tier 1 corresponded through email, and they all scheduled the interview themselves. Nothing was done through an assistant or scheduling representative. Interviews were conducted from Monday, October 14, 2019 to Friday, December 20, 2019. Six of the interviews were done face-to-face in one of the following locations: Nashville (n=2), Thompson's Station (n=1), Kingsport (n=1), and Johnson City (n=2). Four interviews were completed by telephone. These participants were located in Nashville and Memphis. Due to logistical difficulties, these participants elected to have their interviews done over the telephone. The face-to-face interviews were conducted at the participant's choice of location which included work offices, personal residences, university campuses, and hospitals. Each location offered a place where the participant felt most comfortable and all IRB requirements related to confidentiality and privacy were met.

Interviews were scheduled for a predetermined time. At the beginning of each interview, introductions were made, and the IRB approved consent form was reviewed and signed (Appendix E). Each participant received a copy of the consent form for their records. Before beginning the interview, participants were advised that they could skip any question they did not want to answer or stop the interview at any time. Each interview was audio recorded with the participant's permission, and the participants were informed that the recorder could be turned off at any time if they elected. Two participants requested it be turned off once during their interview, for a brief moment, as they discussed a personal topic they wanted "off the record".

Tier 2 Interview Procedures

Interviews were scheduled in two different ways, through email or by telephone. The majority of the participants in Tier 2 corresponded through email, and the majority of the interviews were scheduled by the legislator's executive assistant. Interviews were conducted from Monday, March 2, 2020 to Thursday, April 23, 2020. Five of the interviews were done face-to-face in the legislator's respective office in the Cordell Hull State Office Building in Nashville. These five interviews were all completed on Monday, March 2, 2020. Eight additional interviews were originally scheduled to be completed in Nashville on Tuesday, March 3, 2020, but a tornado hit east Nashville early that morning and the Cordell Hull State Office Building was closed. All eight interviews were rescheduled for Tuesday, March 17, 20202, but on the afternoon of Monday, March 16, 2020 the Cordell Hull State Office Building was closed indefinitely due to the COVID-19 pandemic.

In order to complete additional legislative interviews, I continued to email the offices of the eight legislators who had previously scheduled interviews. Of those, four agreed to participate from their homes. Two provided their personal cell phone numbers for phone interviews, and two agreed to participate via video conferencing. Each location, whether face-to-face or remote, offered a place where the participant felt most comfortable and all IRB requirements related to confidentiality and privacy were met.

Interviews were scheduled for a predetermined time. At the beginning of each interview, introductions were made, and the IRB approved consent form was reviewed and signed when available or orally agreed to if not face-to-face (Appendix E). Each participant received a copy of the consent form for their records either in person or by email. Before beginning the interview, participants were advised that they could skip any question they did not want to answer or stop the interview at any time. Each interview was audio recorded with the participant's permission, and the participants were informed that the recorder could be turned off at any time if they elected.

Data Collection and Transcription

During the interviews, open-ended questions were employed to allow respondents to provide full and detailed responses about their experiences. The interviews were audio recorded, fully transcribed replacing participants' names with interview identifiers. For the Tier 1 participants the identifiers ranged from E1 to E10. Tier 2 participants were identified as L1 to L9. All identifiable data was removed for confidentiality purposes.

Data Analysis

For the analysis of data collected, various software programs were used. They included QSR International's NVivo® 12 qualitative data analysis software and Microsoft Excel. Each of these analysis tools were utilized for different aspects of the research and in the capacity in which they were designed. For the qualitative aspects of the design, including face-to-face interviews with Tennessee legislators and other stakeholders, QSR International's NVivo® 12 qualitative data analysis software was used for coding transcribed interviews (QSR International Pty Ltd, 2020). Transcription was completed by me and three ETSU work study undergraduate students. These assistants were added to the IRB protocol as study staff.

Coding included identifying concepts and developing and defining categories based on their elements and properties. This stage of analysis was done to reveal major and minor themes. Coding included an initial phase of open coding on all nineteen interviews, followed by focused coding on all nineteen interviews to organize nuances (Emerson, Fretz, and Shaw, 1995). Microsoft Excel was used to keep an organized database of participants, and other information vital to the success of this project.

Primary Coding

After the interviews were transcribed, they were printed and reviewed. The transcripts were reviewed from an inductive viewpoint and key concepts and themes were identified. This method allowed for the data to be examined and codebooks created for both the Tier 1 (Appendix F) and Tier 2 (Appendix G) interviews.

Secondary Coding

The transcriptions from all 19 interviews were uploaded into the NVivo® software and divided into two projects to separate Tier 1 and Tier 2. The codebooks for both tiers were used to create nodes and sub-nodes for secondary coding. After this process was complete, a second review of all codes was completed to ensure coding accuracy. Reports summarizing all coding were generated in NVivo® for both tiers.

Themes and Data Display

Data from the interviews were summarized according to concepts and themes and relevant quotes were selected to highlight them. This was the only display of findings used for this study. It was determined to be the most appropriate way to share the findings due to the detailed responses given by participants. The attempt to quantify data was futile as there were no dichotomous responses given during both the Tier 1 and Tier 2 interviews. Even responses that had either a supportive or opposing tone, were typically paragraph-length answers that needed to be displayed in their entirety. The findings of the data analysis are revealed in the following Chapter.

Node Trees

A node represents a code, theme, or idea drawn from the data collected during a study. The two node trees that resulted from the primary coding of this research reflected the concepts and themes discovered during transcription and were used during the data analysis of this research. Complete codebooks with all nodes, sub-nodes, child nodes, and descriptions for both Tier 1 (Appendix F) and Tier 2 (Appendix G) can be found in the appendices.

Chapter 4. Findings

This section presents the findings of the study. The results are guided by the Multiple Streams Framework, which includes three streams: the problem stream, the policy stream, and the political stream (Kingdon, 2014). The problem stream examines the perceived problems with end-of-life healthcare in Tennessee, the policy stream examines suggested policies that could improve end-of-life healthcare in the state, and the political stream section examines factors that impact the political process in addition to attitudes toward recommended policy. The data presented in the problem and policy stream sections are based on Tier 1 interviews with leading experts in end-of-life healthcare. The data presented in the political stream section are based on the Tier 2 interviews with state legislators. In this chapter, I first discuss briefly the operational definition of end-of-life healthcare and the motivation behind participation in areas of work relevant to it. Following is a presentation of the most prevalent themes that emerged from the interviews, with data that are exhibited through relevant quotes.

End-of-Life Healthcare Explored

An Operational Definition of End-of-Life Healthcare

Respondents were asked what they thought of when they heard “end-of-life healthcare.” Their responses encompassed numerous ideas and concepts that included palliative care, hospice care, lifelong care, location of care, planning for future care, a terminal diagnosis, a time frame, and others. Participants typically mentioned two or more thoughts when describing what end-of-life healthcare meant to them. Through the interviews an operational definition of end-of-life healthcare was developed that incorporates five main concepts: a diagnosis, a timeframe, the type of care a person receives, the location of care, and planning for the future. Diagnosis usually refers to a life-ending or terminal diagnosis from a doctor. According to one participant:

> I think of it primarily as someone who has been given a diagnosis that is certainly life limiting, if not completely life ending. I mean we are all going to have an end of life, we just don't know when it is. (E5)

Timeframe most often refers to six months or less to live, but can also mean the last two years or the last two weeks of someone's life as explained by one respondent:

> I think of that more in the context when people have been given a definition of an ending that may be a month away, and that may be years away, but you know it's there. But the journey… starts today, the day they found out. (E5)

Several participants mentioned the different types of care a person may receive as part of end-of-life healthcare, including hospice care, palliative care, or continued treatment:

> I think of palliative care and hospice care, but a lot of people just think hospice care. But the reality is a lot of patients aren't ready to accept or ready to talk about hospice care. So palliative care ends up being that end of life care. (E1)

> I think of palliative care and hospice. I think of… if we're doing it correctly… I kind of have two mindsets. (E8)

Location of care refers to the place where the care is being done. This include one or more different places at different stages during end-of-life:

> When I hear end-of-life healthcare I'm just thinking, "where is their healthcare going to take place for the end of their life?" You know… whether their end-of-life healthcare is going to be at home… or is it in a community nursing home… is it assisted living… is it in the hospital? So where… that's what hits me when I hear that. And who is taking care of their end-of-life healthcare? Is it… are they under hospice care or are they in ICU? You know… with internal medicine… you know, trying to do everything they can to keep them alive, or what are they doing to keep them comfortable? (E9)

> I think of comfort measures and you know, dignity and respect. I think of keeping the people at home. That's what I think when I think about end-of-life. (E10)

The fifth part of end-of-life healthcare's operational definition is planning for the future care. This includes discussions around goals of care, having an advance directive or living will, making one's wishes known, and whether or not the patient values quality of life or quantity of life. It can be something that is discussed years in advance or days before death. One participant explained a view shared by several respondents:

> What I think about is quality of life, you know? What should that end of life season look like for these patients, dependent on what they really desire it to be. What's quality of life for them and how can we provide care that honors that? (E1)

Others shared this long-term perspective of planning:

> Well, I see people over a long period of time. So, my view of end-of-life care is a future, planning for your future care. So, if you have a long-term illness, I think looking to the future… how you'd want… "your kidneys are starting to fail… would you ever want to go on dialysis? Tell me your goals of care. We're going to do everything to forestall that decision, but ultimately your illness might lead to something like that. Would you want that?" So, I think that as a, when I provide a primary care perspective to the patient, I try to get an idea of where they want to go. (E4)

> We need to switch it to make it something that is a routine conversation early in someone's life that is revisited frequently, because it changes depending on where you are. We need physicians and healthcare providers to get more comfortable with death, because right now we see it as the adversary that we've got to beat, and the reality is we're always going to lose. The moment we go "it really isn't about that, because yes, I've got all kinds of things I could do for this cancer, the question is you're the one with this cancer. Here's what the consequences are? Here's what happens if I don't treat it. What is important to you? What do we need to do?" Right now, we have more people dying where they would least want to be, which is in the hospital tied with tubes, not visiting family, no pets, not getting to do all the things they love. Because… we're unable to say to somebody "that's a horrible way to die" and, we need to get more comfortable in medicine saying that. (E6)

In addition to the five main concepts around end-of-life healthcare, several of the respondents said it made them think about gaps with isolated pockets of excellence. That there are "hit and miss" good areas of end-of-life healthcare, but that in a lot of ways, we miss the mark:

> I think that there's a lot of people who are concerned with the care of the imminently terminal and the dying who do great handholding and caring. I think of the great advances that we've had systematically, programmatically, and clinically over the last two decades…. So, I think of improvements, but I also think of gaps. I think that unfortunately the healthcare system in America is still inverted. The primary care base is not good, and the outpatient base is not good. We don't have any real approach to care that's geographically based, or population health based. It's, it's mostly about tall

> buildings and subspecialties. About 95% of U.S. graduates go on to complete a subspecialty and so, with that being the case, continuity of care um… is at a premium. And when you don't know the patient, it becomes difficult to form those deep relationships that make good palliative care possible. You know, still in America now, depending on which area of the country you look at… which demographic you're cutting it with, the average length of stay or the median length of stay in a hospital is 11 to 14 days. That's plenty of time to do good symptomatic work. It is far too little time to do good psych, social, and spiritual work. (E7)
>
> To get the full benefit of end-of-life healthcare, you have a well-rounded team that is focused on the patient and their family, to make sure that they have the most support that they can possibly get. Where they're loved on by people that know them, and their symptoms are managed, and their family is supported. But… my other train of thought is, I think that the current healthcare field does end-of-life care poorly because we don't want to… quote unquote… give up on patients or make them lose their hope. So, they're going to do everything possible to keep them alive, and they forget that death is inevitable. So, we put people through all of these treatments, all of these hospitalizations, until there's literally nothing else, and then you say, "oh it's time for hospice." That's where you have people come on hospice that are on hospice for… hours, or maybe just a couple of days, so they don't get the full benefit of what hospice has to offer. Then they pass away. You know? So, that's a long-winded answer just to say that the way that healthcare does end-of-life… I think that we have a long way to go. (E8)

One participant shared that end-of-life healthcare made them think of missed opportunities and misunderstandings. Missed opportunities in the ways in which patients approach hospice and palliative care, and how they miss out on quality when quantity takes a front seat. There are misunderstandings in how hospice makes people think of death, and how the lack of conversation between patients, their doctors, and family members can lead to misunderstood goals of care, among other things:

> I think of… missed opportunities and misunderstandings and all kinds of things like in... They did a study recently and 29 to 30% of MD's still think palliative care means hospice. And we still have lots of patients that we talk to that think hospice means we take away your food and your medicine till you die. And there's a reason why they believe that… it's because it was true 20 years ago. It wasn't that hospice was doping people up and taking their medicine away because they were cruel, or didn't know what they were doing, it was because people were referred to hospice within three days of their demise. (E3)

Motivations Behind End-of-Life Healthcare Involvement

What motivates a person to choose a career in end-of-life healthcare? Tier 1 participants were asked how they came to be in the career that they are currently in. Most respondents had several reasons that included having a passion for it, the excitement of being part of a new field of medicine, a job opportunity, a personal interest, and because of a personal experience with death and dying. The majority (n=6) of participants had experienced the death of someone close to them as a teenager or young adult and it brought them up close and personal with end-of-life healthcare. Those experiences were an integral part of deciding their career path:

> Yeah, my mom had… linitis plastica. She died the worst death to this day that I've ever seen... nobody knew what to do and they did everything wrong, and she died over a period of two years… but the last two weeks were the worst. She was vomiting up fecal matter and she had multiple obstructions and she was begging to die. They just told her "Well, it won't be too long now." There wasn't anything they could do. And so, when I had my one lecture by my program director at the time, on end-of-life care, as a first- or second-year resident, I really paid attention. And then there was… I just didn't want anybody else's mom to go through what my mom did. (E3)

> My stepfather died my senior year in high school of multiple sclerosis. And at that time, we didn't know anything about hospice, and I realize now how we would have benefited from hospice services for him. We hired a private sitter to sit with him. And now, understand what I said, we hired a private sitter… my mom was a single parent. We lived in a $3,000 mobile home and calling it a mobile home is being very charitable on both counts. It wasn't very mobile… and it wasn't very homey. So, for us it was a tremendous financial and personal sacrifice, and we would have had such a benefit if we had known 30 years ago about the hospice benefit. You know I think, looking back, some of those experiences certainly… I didn't realize that they were constantly shaping my career decisions… but I realize that subconsciously they sort of set the template for me being… having empathy rather than antipathy towards people with chronic illness, and families who deal with chronic illnesses. Whereas some people are just wired to be orthopedic surgeons you know? "I know something's broken and I want to fix it." Whereas I've kind of always been kind of wired toward "wow this is really a tough situation, so how do we lean in and try to make your life a little better?" I, I tell my patients now "I'm not really good at fixing anything, but I'm really great at making most things better. So, you know, if you need a cure, I'm not your guy, but if you need to feel better about things, I'm awesome." (E7)

> My grandfather was diagnosed with Alzheimer's and passed away back when I was 17, and he was under hospice at that point, in a facility… and I didn't connect the two, but I

> had said from that moment on I knew I wanted to be a nurse. I said that the way she (her grandfather's hospice nurse) helped our family, I wanted to be that for somebody else. (E8)

Others said they had a passion for it or felt drawn to it after working in other closely related areas of medicine:

> I just fell in love with end of life care. People are very vulnerable, in vulnerable situations, vulnerable environments in their home and so uh you really get to know people in those situations. (E1)

Whether the motivation to work in end-of-life healthcare or a closely related field came from personal experience, having a passion for it, or other reason, all of the Tier 1 participants shared a common drive to be in their given profession.

The Problem Stream

A series of questions assessing the current state of end-of-life healthcare in Tennessee were asked during the Tier 1 interviews. These questions addressed aging in Tennessee, hospice care, perceived strengths and weaknesses of Tennessee's end-of-life healthcare, medical school education around death and dying, advance directives, and caregiver support.

Aging in Tennessee – The Gaps

Two questions were asked to assess issues around aging in Tennessee and the state's ability to meet the demands of the aging population. One of the most common discussions during these questions was about gaps. The majority of participants (n=8) included gaps such as not having enough facilities, the need for caregivers, the lack of providers, gaps in Medicare, not having enough funding, and not being adequately prepared for the future need of the aging population.

Participants expressed a concern for the lack of facilities that care for the aging population, and the increased need for them in the near future. These include nursing homes, long-term care facilities, assisted-living facilities. Comments supporting this view include:

> We don’t have good social support… and so just to look at the Alzheimer’s population, to house all of those people in healthcare facilities is going to be a physical impossibility. (E7)
>
> We are not prepared in any way for it, especially facilities, because nursing homes cost so much money. So, now a lot of the nursing homes are converting over to rehab and skilled care because they make more money versus long term care patients unless they’re private pay… and we’re just not going to have the expertise in the field and we’re not preparing for it at all, and it’s just gonna be… the amount of money… we’re just not putting the money towards it. Building facilities and getting people educated. (E9)

One of the concerns around having a lack of facilities was that it would increase the need for home caregiver support. Three (n=3) respondents expressed their concern around this issue represented in these statements:

> I see patients that really need caregivers, they really need 24/7 nursing care, and they can’t live alone anymore, nor do they have the family support. So, a lot of times what I do talk about when we talk about gaps, is that you know these patients, they just can’t live alone. Nor can they afford to live in a skilled nursing facility. (E1)
>
> If your aging population is higher than your caregiver population, then we’re going to have a little bit of a problem… and that’s not something Medicare pays for. They don’t pay for caregiver services. That has to come out of pocket. Which is… you know a lot of people can’t afford that. (E8)

Gaps in Medicare and State Funding

Another gap that the majority (n=8) expressed concern about was Medicare’s limited coverage, and the lack of funding for the aging population’s healthcare needs. Participants discussed freely the benefits that Medicare will and will not cover, and that it does not cover everything. Medicare is an insurance payment plan for senior citizens. When people reach a certain age they qualify for Medicare, and it will cover health services, hospital stays, doctor visits, and medication. It does not cover assisted living facilities or in-home 24-hour caregiver support. Respondents discussed their concerns regarding this issue:

> So long-term care is very expensive. The way the system is built…okay, so you have a lot of people who encourage people to save, so they have money in retirement. So, what happens is when they get ready for long-term care, they spend down and end up on Medicaid, which means that we pick it up. I mean the taxpayers pick it up. I can't figure out why we don't… we suggested to the federal government that they look into seriously about picking up long-term care services under Medicare. Medicare…basic Medicare doesn't cover vision care, dental care…hearing. It's like, wait a minute, as you get older, those are the things you need. (E2)

> Not too many years ago Tennessee's long-term care Medicaid funds went 98% to the nursing home, 2% to home and community-based services. It's about 50/50 now. And then you have the more progressive states, and it is a good change, are quite the opposite. 30% to the nursing homes, 70% to home and community-based based services. We're not quite there. So, that would be a way to spread the funds around and keep people at home. Which is where they often want to be. It's possible to provide that kind of safe and adequate care in the home. Um… but just in terms of other health measures. This block grant plan, I hate to get too political but… is a horrible thing for older people who are poor. The state thinks they're going to save a billion dollars by going through this block grant, but we're already in the five lowest states as far as reimbursement… or cost of care per capita for the Medicaid program. So, there's not much fat in that budget, and plus it's a 50/50 match with the feds currently. So, if they're going to save a billion dollars, there's going to be a deficit of two billion dollars… two billion dollars of care. And who are they going to take it from, but the higher cost people? Oh my gosh that's awful. It's just an indication of the attitude of unfortunately, the policymakers in our state. It's an insurance plan… it's not a healthcare plan. (E4)

Lack of funding went hand-in-hand with concerns around Medicare. Four participants specifically mentioned funding being a concern with keeping people at home or providing them a place to stay in a qualified facility:

> I would imagine it's gonna take a large financial toll on the government, you know at a state level but also nationally. There's a lot of gaps… there's not gonna be enough skilled or palliative providers to care for all of them. So, I would say the biggest need or the biggest gap we are gonna have is there's just not enough funds maybe to pay for all the patients who need a place to stay. We will have to come up with more facilities maybe. (E1)

One participant shared their concern about a lack of funding, and the impact it has on patients and their caregivers. They shared a story about one of their patients who had heart failure and needed assistance:

> I have very dim views of Tennessee's provision of services for home community services for the elderly. It's awful. Nationally we haven't done that much better. About ten years ago there was an act passed by congress called the CLASS Act. That's Community Long-term Services and Support. It was rescinded almost as soon as it was signed because it required a half percent payroll tax by everybody working. That didn't go over very well. They took it away. That would have been the long-term care insurance. I had a woman in my office today who has heart failure. She's in and out of the hospital all the time and her daughter says, "I'm getting worn out. Can't we get some homemaker or home health services?" Well she's not a veteran and she… that community options program could be a possibility, but there's a 5,000 (person) waiting list. There's no help for folks like that. But the Long-term Care Services and Supports program, would have done that for somebody like that. So, she will keep bouncing into the hospital and the family, the caregivers, are getting burned out. It's awful. We aren't doing a good job. (E4)

Lack of Providers for the Aging Population

Half (n=5) of the participants discussed their concern about the shortage of geriatric trained providers available to care for the aging population. The field of geriatrics is relatively new in the history of medicine, but it is now considered a specialty and a lot of older people prefer to see a geriatric doctor. One respondent explained that geriatrics is for the older population what pediatrics is for children:

> Geriatrics and pediatrics are a lot alike. I mean you know… patients work through developmental stages, you're worried about how they're fed, how they're housed, who's taking care of them. With teenagers you fight over the car keys… with Alzheimer and dementia patients you fight over the car keys. It's the same kind of conversation, like who they date when they're not under your direct supervision. It's the same. (E7)

Two participants discussed primary care and how there is a shortage of primary care physicians who could fill the role of a geriatrician for their patients, since a lot of people get their care from their primary care physician:

> There aren't enough providers, and I'll include nurse practitioners and physician's assistants, with specialty training in geriatrics to take care of all of the older people. So,

> our educational mission has been for many years to make sure that each provider is a good geriatrician for their own patients. So, you may be a family physician. You may be an adult nurse practitioner. But when you see that older person, you'll think about them differently. (E4)

> So, one of the challenges we face that I think impacts end-of-life, and is important with the boomers all graying, is that we don't have enough primary care physicians. Because if you really want to impact the quality of that critical transition, both in terms of most important helping patients and families handle that, but also with less expense, you've got to have a strong primary care base and our country doesn't know what that means right now. To me, when you're looking at what you're talking about… it's not going to be enough for the number of people that we're facing. Because over 10,000 people a day become Medicare eligible in this country. I mean the graying of the boomers is astounding. We don't have enough people who are trained to take care of our older population, and we still don't have people covered by health insurance. (E6)

Others remarked that:

> We don't have enough geriatricians, we don't have enough palliative physicians, we don't have enough, we don't have enough… we don't have district nurses who go out to the home and actually you know… we have a home health system, but it's really designed to do something differently than most developed nations. So, what we don't have is good continuity of care at the base of the healthcare system. We don't have enough workers to manage the bolus of patients that we're gonna have and so, being able to look at public policy in a way that funds home caregivers and we can leverage the power of the family. (E7)

> So, as far as the geriatric nurse practitioner, when I went to school, I was the only geriatric nurse practitioner in the program, and that was back in 2004. So, we currently have a geriatric nurse practitioner student with us on our rotation… guess what? She's the only one in her class. So, there has been no progress made despite it being… you know the geriatrics being the fastest growing population, we are not uh… we're still way behind. We're not making any progress. (E9)

Not having enough geriatric providers to care for the rapidly expanding senior population was another accumulated gap that confirmed the state of Tennessee's lack of preparedness for the boom of the senior population that is expected by the year 2030.

We Are Not Prepared

Participants agreed that the state of Tennessee is not prepared to meet the demands and needs of the growing senior population. It was also stated that on an individual level, people are not prepared either. It is important that we start now to recognize that there are a lot of changes that need to be made, both on a state level and on an individual level. From education, to increasing the number of geriatric doctors in the state, it is important that preparation is made:

> Educating future physicians, future providers, about this change… showing them the benefits of geriatric models, and incorporating them into their practices, is huge. And I think that is basically going to change a whole lot of things. So, someone who knows the way… I guess, can see the future happening… who can plan for it, who can tell administrators what they need to look out for, can help them pick out the sick people they need to focus on… will be more valuable. So, I think that if geriatricians are more valuable, they'll be compensated better, and perhaps that will drive more people into the pipeline. (E4)

Another view on being prepared focused on the individual:

> So, people work, and the majority of people who are working, work very hard… and do the best they can to save money. Okay? But if you look at the demographics across the country, you know like a third of the population has been unable to save any money... And then you got another group that has saved probably $10,000 or less, maybe $30,000. Not a lot of people can save a lot of money, as hard as they may try. You know? It's hard. Something happens, or there's a health issue or something, and they just can't get there. If you don't save any money, you know, you're gonna hit retirement and not have any money. A lot of people think that Medicare will pick up long-term care services. It does not. So, you get to 65 and it's like "uh oh" you don't have…if you haven't saved. I mean the cost of nursing homes is $70,000 a year, maybe more, depends where you are. (E2)

Weaknesses in End-of-Life Healthcare

During the Tier 1 interviews, participants were asked what they thought the strengths and weaknesses of end-of-life healthcare in Tennessee were. Participants struggled to list strengths and if they had any strength to talk about, referred directly to their own employer:

> I can speak for our company because that's the one I'm familiar with, is that we offer 24/7 nursing care, there's just a really large support system for patients and family members so they are able to focus on doing what they are comfortable doing, which unfortunately for most of them just being home and surrounded by their loved ones. (E1)
>
> They (their employer) do many good things. The team approach, the bereavement counseling, the end-of-life care, symptom management… all of those things are good. I think that they show a good model of care. (E4)

> I can’t speak for the whole state, I can speak for (their employer). I firmly believe that they provide the best end-of-life care possible, and they’re really patient focused. So, every patient has individualized care. We don’t turn anyone down for inability to pay or complexity of situation. You know… so, I think that that is one of my most favorite things about (their employer) is that we don’t back down and we don’t say no. As long as somebody’s willing to try…we don’t say no. (E8)

Additional strengths included that the awareness of end-of-life healthcare needs is expanding across the state (n=1), that there is a renewed interest in end-of-life healthcare (n=1), and there is strength in the medical community (n=1):

> I would say… it’s growing. Like the presence of hospice like in our town just last year we got a new hospice unit. (E10)

Strengths can also depend on where a person lives in Tennessee, urban versus rural. People who live in an urban area like Memphis, Nashville, or Knoxville, are going to have more access to good end-of-life healthcare, good hospice facilities, better support, and more resources than people who live in rural areas:

> It’s different in urban vs rural markets. Wildly different. I would say in the Nashville area, proper middle Tennessee, which is what I know. I can’t speak to Memphis or anything. I have lots of hearsay info, but no factual. But in middle Tennessee we are very fortunate to have very good hospice programs. (E5)

There was also a discussion about medical advances. When healthcare advances, then tests, treatments, and medications advance. This leads to an improvement in end-of-life healthcare when it comes to the actual treatment of disease:

> I think that there is a renewed interest in this part of life, part of illness, and uh… that’s a good thing. (E4)

The limited response to the question about end-of-life healthcare strengths in Tennessee is, in itself, a weakness. Compared to strengths, where only 60% (n=6) participants had an answer, 100% (n=10) of participants discussed weaknesses. When asked about the weaknesses, participants were quick to share various areas where they saw the need for improvement. One respondent shared their initial reaction to the question:

> So, we can get your pain under control in 24 to 48 hours, but we can't help your family deal with anticipatory mourning, and grief, and unpacking spiritual issues in that amount of time. If a team does so… it's not medicine, it's a miracle. It's not palliative medicine at that point, it's a palliative miracle. So, I think that um… it still is a challenge… I think as we enter the post-modern era of medicine, things have gotten… things have gotten better. The great lie of the modern era was "If you do enough 5k runs for us, and build a building tall enough, and throw enough NIH money at it, we'll solve every problem." I think rightly so, people have pushed back on that, and said, "Wait a minute, what are we doing?" And we're realizing that for some chronic illnesses, the rescue medicine model just is a poor model of care. We isolate people in the ICU… you know, we reverse their day/night cycle, wake them up at all hours of the night with beeping machines, don't let them see their family, and call them the patient in 202 rather than Mrs. Jones who has CHF exacerbation. Then we're shocked when there are poor outcomes. So, I still think that society in general is getting it. Still don't know if the medical system has bent yet to… to… appreciate that reality fully. (E7)

Hospice Care in Tennessee

Sixty percent (n=6) of the participants mentioned hospice care when discussing end-of-life healthcare weaknesses in Tennessee. A separate question was also asked to assess the participant's opinions on the low number of residential hospice facilities in the state. Though there were weaknesses discussed, three (n=3) of the participants explained that there are other options for hospice care besides residential facilities. These include nursing homes, hospitals, long-term care facilities, and hospice care can also be in the patient's home. That is probably one of the most common places to have hospice care:

> Well 90% of hospice care is, we're talking not palliative but hospice care, is provided in the home… and it was originally started as a home health program. The addition of inpatient hospice residences is a rather new thing. (E4)

> All hospices have a two-week and it's not two-week. Okay, so what it is… is you have to meet criteria to be in it… Six hospice houses doesn't mean that that's all the beds there are, because we have infinitely many beds that we can take those exact same patients that would go to the hospice house here in the hospital… You have to have a symptom that cannot be managed at home to be in GIP [General Inpatient Care]. It's not a two-week maximum and there's no two-week maximum at the hospice house in Bristol. That's a

> myth. They recommend that there should be less than two weeks. Okay, because what person’s symptom is gonna take two weeks to get under control… that’s really the thing. But there's no maximum amount of time, it's however much time it takes to get that person’s symptoms under control. (E3)

Weaknesses with hospice included lack of facilities (n=3), money’s influence (n=6), lack of financial resources (n=4), stigma around hospice (n=3), and late referrals to hospice. Being referred to hospice too late was reported by 40% (n=4) of the participants:

> Well if all the referrals (hospice) are being made at the time they should be made we would see people’s average length of stay almost right at the six-month mark or higher. We have some hospices here in town that get referrals from the specialists, like oncologist or neuro, and their average length of stay is two to three weeks. To me that means they were referred way later than they probably should have been. Now I don’t know “what was the reason, or the incentive?” I can’t speak to that. I have no facts. But I could just see everyone’s incentive system, and I could see the end result, and it makes me wonder. (E5)

This participant felt that hospice was being referred too late and questioned the reason or incentive for it. Ulterior motives will be discussed in another section. Two other participants shared their view of late referrals to hospice:

> So, I think that is one of the biggest, biggest issues… is waiting until someone is right… is knocking on death’s door before you put them on hospice. I know that… I’ve witnessed in oncology, the oncology world will bounce patients back and forth between the routine treatment, and then when that fails, they bounce them into a trial. Then when that fails, they bounce them back to a second line therapy. Then when that fails, they just keep bouncing back and forth on a cancer that you know is not curative. All because we don’t want to give up hope for the patient. Nobody’s had that conversation with them (the patient). So, I think that’s one of the biggest issues. I think that traditionally, and healthcare in general, and I think hospice can sometimes fall victim to that. Is recognizing when someone is still upstream but still eligible. So, Medicare puts some pretty strict criteria around admission to hospice, and what qualifies and what doesn’t. But… people are not black and white… it’s a very gray area. Very few people fit into the check list boxes. So, it’s being able to kind of look outside of that to prognosticate and figure out who has six months and being able to get them on earlier. That way they can reap the full benefits of hospice. (E8)

> People are holding on to like, home health, and not wanting to go into hospice yet. Then they waited too long to get the full benefit. That is the problem, I think they wait too long, and I don’t know what could be done just besides… it might have to start with the doctor. Like, you know, we’ve been in a society where death is a bad thing and I feel like

> if we didn’t have that mindset, if we thought of it as a celebration or as important as birth, then that would change… you know. These old folks, they’ll do whatever their doctor says, but if he’s talking rehab when you’ve got a terminal illness, then that puts them in a different mindset. So, maybe it would have to start with more educating doctors better on end-of-life care that way they can start having those conversations early. (10)

During the topic of hospice care, money was discussed by 60% (n=6) of the participants. Weaknesses included that there is a lack of funding (n=4), Medicare has limited coverage (n=2), and TennCare does not pay enough (n=2). Some residential hospice facilities will not even take TennCare because it doesn't pay enough:

> Many hospices will contract with long-term care facilities and use that space to provide the hospice care. The problem with the residences is that there are… the financing of that is difficult. See the hospice benefit is an outpatient benefit. It’s a home benefit. It’s a care service but it’s not a bed and board service. (E4)
>
> I’m usually incredibly optimistic… but catch me on a topic and give me an opportunity to be a little cynical. I’m afraid that a lot of changes don’t happen because of money. It’s either because there’s not enough money to do the right thing, or someone’s making a lot of money to do the wrong thing. And it’s very hard to shift it, and it requires… usually a community-based conversation. The change here is not a federal change, it’s probably not even a Nashville change, but it probably is within a community. More conversations among everyone and the provider. I really think a lot of what you’re asking for, especially locally we don’t have enough hospice, well you’re not going to get that from Nashville. What you are gonna do, if you can go to communities and say, “Let’s have some conversations. What are your needs here? What do we need to do better?” It may be a primary care workforce. It may be hospice. It may be, who knows. (E6)

It was also shared that the Medicare hospice benefit is an outpatient benefit. It is a service, not room and board. So, if when someone needs residential hospice, it is only covered temporarily for family respite care or to get symptoms under control, it is not covered long-term:

> The problem is not just… the problem is not just… the beds, the problem is the funding. The way that the Medicare benefit is structured for hospice services, room, and board in a hospice facility, is only paid for if a patient has general inpatient status. And most of those general inpatient stays are less than seven days because the documentation burden required to receive inpatient designation, which by the way has to be done every day, is robust. And so, even though a facility is there, keeping it full even with a large hospice, can be difficult because most patients can’t afford the domiciliary fee which ranges from $150 to $225 a day. So, it can be as expensive as a very high-quality nursing home, and the family… they’re being asked to foot that bill. There are a number of charitable efforts

> that hospices make to provide reduced cost and free care, but still uh… it's a bake sale mentality for a societal problem. (E7)
>
> For somebody who doesn't want to die at home, or somebody that… they have an elderly spouse that just can't care for them… they have to pay room and board for that. So, that's not something that Medicaid covers. That's where it gets a little bit tricky. All that to say, the reason… there aren't more residential hospices (pause) we actually lose money on the residence. You don't… you don't make money on that. So, with our hospice being non-profit, because we have people that donate money and those sorts of things, it helps us to keep the residence afloat. So, that we can afford to keep it open. But it would be really difficult if you were a for-profit agency, to keep a residence like that open. (E8)

The idea of hospice care being a service and not a room and board option is a concern for people who may have a family member who is unable to care for them at home. Hospice does not come to a patient's home every day, all day, all night. Hospice typically comes to someone's home a couple times a week, maybe three times a week, to check on the patient, to check on medications, to help change the patient's bed. They are not there 24-hours a day. Taking care of someone who is dying is not easy:

> Some caregivers don't want loved ones dying in the home and they want that extra support, but they also can't pay for skilled nursing facilities, so there's a conundrum. I learned the hard way. I came in and was so gung-ho about having good goals of care conversations. When patients came out of the hospital and they'd be in the skilled nursing facility maybe a couple days, and I'm like you know… really telling them about hospice care and they say, "Yeah that sounds great", and then I go tell a social worker the family is ready for hospice care. Well, what I found out is that if they transfer from skilled to hospice, they lose their Medicare coverage for their stay… So that, that's a huge problem. So, I think we need much more support. (E1)
>
> Sometimes they don't want to take care of them at home. They don't want them to die at home. They don't, you know, they just don't have that coping mechanism. (E10)

Provider Shortage

As was discussed with the aging population and the need for geriatric specialists, staffing in other areas of end-of-life healthcare can be a problem when it comes to the number of staff available, staff turnover, training, education, and the need for end-of-life healthcare specialists.

One of the reasons that staffing turnover is a problem is because end-of-life healthcare work is hard. Not just physically, but also emotionally. So, unfortunately staff turnover is a problem:

> So, staffing, there's a lot of staff turnover and then you have to retrain and not everyone's comfortable with end of life right away. So, you know you have your seasoned nurses that are really good. Then you have nurses and aides that come in that maybe their heart's not in it. (E1)
>
> When I went (to geriatric nurse practitioner school) in 2004, I was the only student, and still today there's only one student (in the program), specializing in care of the older adults. Even in the medical field, there are 150 openings right now and they can't find any geriatric specialists. So, that probably… that goes hand-in-hand that you just don't have that specialty in end-of-life care because a lot of… you've got your internal medicine and family is all big, and that incorporates geriatrics and hospice of course… but I think to have that little specialty… you've got your pediatrics when we're born, that's a specialty. Well I think geriatrics and end-of-life is a specialty, and we just need a lot more. (E9)

Related to staffing issues was the topic of primary care. Two (n=2) participants felt that sometimes a person doesn't need a specialist for end-of-life healthcare, they need a good primary care doctor. Someone who knows their health, who knows their history, who they are comfortable talking to and making decisions with. Right now, the lack of primary care providers is a significant weakness, not just in Tennessee, but across the United States:

> I think the challenge we have in our state, particularly in federal markets, there are giant education gaps to what hospice and palliative care even is. And that knowledge gap extends into our clergy as well as the medical community. Secondly, there's just no primary care in rural markets. So, if you are an individual in a rural market, where do you go to find a physician to make a referral? (E5)

Caregiver Neglect

The need for expanded caregiver support was discussed by half (n=5) of the respondents. Not the caregivers in the hospital, nursing homes or residential hospice facilities, but the family, home-based caregivers. Respondents repeatedly described home caregiving as emotionally, physically, mentally, and financially exhausting:

> I did a preliminary study on COPD patients and their caregivers after, in the 30 days post hospitalization, because you know they typically go right back. And yeah, they really, the caregivers need so much more support than they are getting and a lot of times… I mean I've had patients where their caregiver ends up dying before them, because they are so stressed out. I think "wow". Some of them are my age and are picking up their kid at school, taking their dad to a doctor's appointment, visiting their mom in a skilled nursing facility and I'm like "Oh my gosh, I don't know how you're doing that right now." It's hard, and their sandwiched. Our generation, they're sandwiched in between the kids and their parents. (E1)
>
> I think a lot of it is that there is a lack of support for caregivers but there's also… there's a lack of caregiver understanding of it. You know, what I'm trying to say is that the denial part of hospice, going onto hospice, and then following the death or whatever, people do feel abandoned and that's one of the things that we get in our surveys a lot… like after death, families feel like we just, we drop them. We're gone. You know we're in there for weeks at a time, a bunch of us, a whole team of us, and suddenly their loved one dies, and they're just left alone. That's one of the things that you know, I feel like as hospice, you know not just our company, that we have to work on support for the caregivers. (E10)

One participant talked about how when they have a patient who is terminally ill, or near the end of life, they actually have two patients. They have their patient, and they have the patient's caregiver:

> Support for the caregivers. Yeah, when you have someone with a chronic illness, someone who's dying, you've got two patients. You've got a caregiver as well. Focusing on their care and getting them help, can be tricky. It depends on what benefits the sick individual has. So, we're really weak on the caregiver really. It is really stressful. In fact, I have examples of caregivers uh… this was in the case of dementia patients… the patients were so hard, I had caregivers commit suicide. Isn't that terrible? Talk about despair… that's awful. You wonder if increased caregiver support would decrease emergency room use and hospital stays. (E4)

Having Difficult Conversations

Having difficult conversations was a recurring topic that came up throughout the Tier 1 interviews. Having difficult conversations can be between a doctor and a patient, a terminally ill person and a family member, family members and the doctor, or it could be a combination of one or more of these groups. According to the respondents, having difficult conversations is something that can impede good end-of-life health care. It can stop people from receiving the treatment that they need to receive or want to receive, or it could actually cause someone to receive treatment that they don't necessarily need or want:

> So, I would say definitely access to care, we're not getting, you know patients aren't getting referred when it's appropriate to get referred… docs are having a hard time having conversations about end of life. So, you'd be shocked how many patients are practically on their death bed and the doc just really hasn't even mentioned it or maybe even thinks "oh no, they're not even appropriate for palliative care," and we're thinking, "wow." (E1)

> Think of how many times, and I'm sure you can come up with many examples, people go in, have something done, don't know why it's done, don't know what's up, don't know what the results are, come out of it and then are shocked because no one said this could be cancer… So, we're talking about end-of-life… this is another part of that conversation. You need to be able to sit down with someone and say, "What do you know about this type of heart attack?" (patient says) "It's a heart attack but there's so many great things you can do." "No, this heart attack killed most of your heart. There's not a whole lot we can do. There are some things, but I just need you to know what this is." We don't have those conversations. We go "Sure… we'll put you on these meds, we'll send you to Vanderbilt to see this specialist…" The bottom line, your heart's gone. (E6)

Another respondent shared how family members not having these difficult conversations can impede end-of-life healthcare decisions:

> I know my mother-in-law, she's 75, and every chance she gets she tells his (her husband's) story. About how hard it was for him to die at home, and our experience with that, and her biggest regret was that the last round of the clinical trials, it took his taste buds. Up until he tried that trial, he loved drinking wine and eating with his family. We stopped that trial two weeks in, because it literally took all the taste out of his mouth and everything tasted like metal. He literally stopped eating. So, the last thing he had joy from was wine with his family, and that was gone. It's the most powerful part of her story when she speaks, because she said, "I think if he and I had been more honest in our conversations, we would have never done the trial and I might have had him three more months, and he would have kept having wine and dinner with his family at night." It's powerful. (E5)

During the discussions about having difficult conversations, participants shared several reasons why these conversations are difficult to have. First, many doctors are not trained to have them.

> I think of… and I know you've seen the data… the amount of money that we spend in the last year of someone's life. In the last six months. It's insane… with no impact on how

> long they live, much less on quality. In fact, I'm pretty darn sure we negatively impact quality of life and spend a ton of money. Some of it's a cultural thing because we can't, we can't accept that death is part of life… and patients are very trusting. It doesn't mean I should come in and say "Let them die", but if I'm sitting here going, and I know doctors, and physicians, and PA's, and nurse practitioners have these discussions, "There's nothing we can do… this patient's gonna die." But instead we go in and say "Well, somebody's got a protocol at Tufts or Vanderbilt. I think we can get them in." We can try again because life is precious. So, let's spend some more tens of thousands of dollars, which by the way the family now goes bankrupt because of the medical bills. Instead of saying to somebody, "I'm really sorry. I don't have anything. I've got stuff that can make you sick. I've got nothing that's gonna give you more. What's important to you right now?" And there will be those patients who say "I don't care. My hair can fall out. I can be sick as a dog and be in the hospital on a machine. I don't care. That's precious to me and I need it." Fine… you get it. But very few people, if you say, "Here's one way you could die versus here's another." You're gonna say, "Oh, that sounds good to me." (E4)

Secondly, doctors are sometimes unsure of the prognosis. They may not know whether or not a new trial drug might work or if a new treatment might work, so they avoid the conversation altogether. The impression given by the participants was that doctors want patients to get better. They want patients to live. They do not want to feel like they're giving up on a patient. They do not want to let the patient or their family down, so they avoid the difficult conversations:

> From the research that I've seen, especially on COPD, is that maybe they're unsure of the prognosis so they don't have confidence in prognosticating and telling patients kind of what to expect… and I think that they don't have the time. Yeah, it takes time to have a conversation like that. (E1)

> If you're gonna take something away from somebody, you got to give something of value in return, and if you're gonna take away their idea that they're gonna live forever, then you got to give them something of value. What are we gonna do about it? We can't fix this problem, but this is what we're gonna do. We always have to give them that and so "I can make you comfortable until the good Lord comes to get you or heals you, one, we believe in miracles. I just can't write an order for a miracle." (E3)

A third reason for not having difficult conversations is that according to two participants, there just is not enough time. They explained that there isn't enough time during appointments to actually have those really difficult conversations with someone. Doctors are sometimes so rushed through 10 to 15-minute appointments, that are scheduled back-to-back, they cannot sit down with someone and talk about end-of-life healthcare, goals of care, or advance directives.

Death and Dying in Medical Schools

One of the questions in the Tier 1 interview guide asked the participants about the current state of education in medical schools when it comes to end-of-life healthcare and death and dying. Half (n=5) of the participants found the lack of end-of-life healthcare training in medical schools extremely difficult to believe and felt that it was higher than the number that was reported in the research cited in the question. One of the comments made was that most medical schools were requiring some form of end-of-life healthcare training, but that it could take time for medical schools to implement them. Two (n=2) participants explained:

> I can't say how all schools are responding to it, but my guess is that 10% is pretty low. To my knowledge they're required now, the American Association of Medical Colleges has a list of things that you have to do and uh… we struggled to get geriatrics on their agenda, but end-of-life care it is now required that they have either disciplinary training with nurses or social workers. So, I don't have the up-to-date rule book now, but my understanding that probably all of them have, and they may be struggling to make the programs effective and work it into their curriculum, but pretty much everybody has something now. (E4)
>
> Oh… it is taught. It's an AAMC requirement. Yeah, the American Association of Medical Colleges uh… absolutely requires them to teach it. So, they do teach it. It's just the kids forget. Because… they don't, they don't rank it as being important. Uh… they remember the things that are tested on, and death and dying is seen as uh… a failure. Not as part of the natural life cycle. It's seen as something that should be avoided, and students are embarrassed by it. So, they don't remember being taught it, but it's taught at every school. (E7)

Three (n=3) participants said that they felt like it was improving and that a lot of the nurse practitioner programs were taking a more active role in end-of-life healthcare education. Some of the oncology programs also require more education in death and dying:

> Now at least they are starting to build it in to the oncology curriculum. So, that's a good start, but that's not the only thing killing people. And so yeah, that needs to change for

> sure. They’re starting to add it I believe into most of the nurse practitioner curriculum. (E1)

Two (n=2) of the participants, who were affiliated with medical schools, said that their programs specifically did offer training in end-of-life healthcare and having difficult conversations. Though they admitted it was sometimes only a one-day seminar or a two-day retreat, not an entire semester or year of a class:

> So, all of the medical students at least get my lecture at the very end, if they pay attention to nothing else, if they come to the Keystone lecture at the very end of their fourth year, they get at least two, almost three hours of me yacking at them about it and then I know that in their simulated patients, there's death and dying scenarios for that. (E3)

> So, one of the things that we do very well, and have for a very long time, is a communications course that includes breaking bad news. So, how to tell somebody they’ve got breast cancer is one of the discussions. Now that’s different than end-of-life, but breaking bad news is a component of end-of-life. So, we have that, but it’s a one semester course, and then it’s done. So, another way of working through this in the system is to make sure that these kinds of communications training go beyond a one semester, one afternoon, small group session. That you really say, “This is what we need.” And that becomes an ongoing part of regular education. The trouble is it is resource dependent. It’s extremely expensive to put on because you’ve got to have standardized patients, you have to coordinate and have facilitators, you have to train the trainer if you’re going to do it right. (E6)

Even though there was some discussion over the accuracy of the data that was reported in the question about medical school education, the majority (n=9) of the participants did agree to some extent that there needs to be more. One of the reasons there is not more education on death and dying in medical schools, is that the medical community sees death as a failure. This revealed that end-of-life healthcare education is still objectionable and not as respected as other areas of medicine:

> Because the medical community, I think they’re trained to intervene and prolong life, so they don’t see death and dying as part of the medical process. They see it as a failure of medicine so, which is crazy. Um, but it’s been the way we have been trained over the years. (E1)

> I think that people have a really hard time saying the word die or dead or death in general, and I think that the mindset for healthcare for so long has been to heal and fix and band aid that again. People forget that death is inevitable. So, because people have such a hard time talking about it, they don't educate on it. I truly believe that if you go into any area of healthcare you should have to have a full semester worth of a class on death and dying, advance care planning, and how to have these conversations. They're really hard conversations to have, especially until you know how to address them, and I think people shy away from them because they're hard to have. I know a lot of healthcare fields that death is a failure on their part, but in reality, we are pushing all of these aggressive, life-sustaining measures… they're not natural. Right? It's not things… it's against the body's attempt to wind down to die. You know? And we're doing all these aggressive measures. Now that is absolutely appropriate in many cases… but when you've got a 95-year old on a vent (ventilator), that's not, that's not appropriate. Right? But having that conversation is hard and it's hard because we're not educating on it. And we're not teaching people about what it looks like for the natural process of people dying, for them to normalize it a little bit. (E8)

Secondly, participants reported that there is a lack of interest in this area of healthcare, and that can impact what is being taught in medical school. According to three (n=3) respondents, very few medical students decide to go into primary care or into geriatrics or hospice medicine. Most of the students now are going into higher paying, higher status subspecialties like cardiology and orthopedics and gynecology:

> So, I don't disagree with you. That's one of the challenges I see. Even if you had more education, 95 plus percent of the med students are gonna go into specialties not primary care. They're going to be a radiologist or anesthesiologist or pathologist or orthopedist. They aren't going to be a family doctor. At Vanderbilt I think it's less than 3% of our medical students are going into anything primary. Because it doesn't pay anything. I mean your debt when you finish that school is two to three times your annual salary. That's your debt burden. Imagine graduating with half a million in debt and making 120 thousand a year. How do you ever crawl out from under that? I think a much more effective place to do a lot of these trainings is in the nurse practitioner programs. (E5)

Lastly, participants were generally surprised that end-of-life healthcare and death and dying were not taught more in medical schools. They all (n=10) agreed that it should be an educational component:

> It just doesn't seem to be a priority. It really doesn't. Just one of the lesser areas, and why? I don't know. (E9)

> It seems like death and dying gets overlooked. Like people don't want to talk about it and I don't know if that's part of it, or they think it's not important. You know what I mean? (E10)

The Green Trail of Money

Throughout the interviews, participants explained that end-of-life healthcare and money were intertwined. Money influences medical schools, hospital systems, doctor's offices, residential hospice systems, the state legislature, the federal government, TennCare, Medicare, Medicaid, private insurance companies, and the list goes on. In each of these areas, money infiltrates even further into detailed and specific areas. Eventually they are all connected and untangling them becomes an overwhelming problem. As one participant explained, even state healthcare policy is a financial issue:

> Do you know our state Medicaid program, the Bureau of TennCare, comes under the Department of Finance? Do you believe that? It's an insurance plan… it is not a healthcare plan. It just shows you… but that is a third of the state budget. So, it's a budgetary thing. We fault the public. You know… by not making their voices known, or they're deferring it to legislators. Now, healthcare policy is very complex. It's hard to understand. Uh… but, right now I think that the people that have the loudest voice are the budget hogs basically. The blame is on all of us… all citizens. I'm hoping that reframing aging and promoting an age friendly environment and community will help show people the error of their ways. But legislators, right now it's all budget, and it's not "well, let's help the poor needy people." Not at all. (E4)

> Our country is still creating this crisis of end-of-life because we're not creating a way for them to come in and have a healthy life. So, what we're doing is more and more people are having diseases that kill them that don't have to, or worse (pause) cripple them. Because actually in a horrible way, from an economics perspective, you'd be better off if they just die because then you don't have to worry about taking care of them. They're not a drain on the economy. I mean, I hate to put it that way, but when you look at it, prevention costs us money because we keep people around longer, and now we're supporting them. There are a lot of societal things that are very much a part of this conversation. (E5)

Ulterior motives in end-of-life healthcare were discussed during four (n=4) of the Tier 1 interviews. The topic came up when participants were asked about weaknesses in end-of-life healthcare in Tennessee and hospice deficiencies. One of the respondents explained that healthcare professionals in certain fields may find financial incentives to continue to treat a patient even when they know it is not curative:

> One of the key things that is being debated at CMS now or Medicare, is that when you start hospice you have to discontinue all other treatments. Now if you're the oncologist, and you've been doing chemotherapy, you basically are referring the patient away and discontinuing your opportunity to see them. Now I'm not suggesting what people do or don't do, I'm just saying that's a pretty perverse incentive. That if I tell someone they have a choice, I'm encouraging them not to use me anymore… and I can't bill for anything anymore. So, you can let that simmer in your brain. (E5)

The participant went on to explain that doctors have liability insurance to pay, they have bills, they have a practice to run. Maybe they do not set out intentionally to do it, but subconsciously the motive is there. When the idea of ulterior motives was mentioned during the interviews, it was done with apprehension. As if the participant was not comfortable admitting their concern:

> I think sometimes there is a financial gain in some fields to continue to treat. (E1)

> So, it's separating the signal from the noise… it's hard. Even in a place like Nashville. Because we have plenty of institutions in this city that will totally administer chemotherapy. Even if you're going to be dying in four or five months. (E5)

Social and Cultural Influences

Discussions around cultural and social norms occurred in all of the interviews (n=10). No question specifically asked about norms, but in the process of answering questions, participants included the following topics: stigma around hospice, high religiosity in Tennessee, Tennesseans being known for pride and independence, and living in a death avoidant culture. Stigma was discussed during 30% (n=3) of the interviews. It came up during the topics of end-of-life healthcare weaknesses, hospice, and advance directives. Hospice is very stigmatized according to respondents. Simply put, people hear hospice, and they equate it with death:

> There's still that stigma attached to hospice. Like you get into an older generation, and you get into somebody that is in their 80's and 90's and you say hospice and they're like "oh no, you're not killing me." I think that's the weakness. Bringing the lack of knowledge and education to the community. (E10)

In addition to stigma, another area of influence reported by respondents was religion. According to two participants, religious influence can sometimes be a barrier to good end-of-life healthcare because it can keep a person from accepting death and preparing for the process of death and dying. According to one participant, religious people can be less likely to accept hospice referrals or palliative care referrals and family members can also express these characteristics when it comes to religiosity. Another interviewee shared that in their experience, people who are highly religious, and have involvement from their community or church pastor, are much less likely to accept hospice referrals or hospice treatment. They are much more likely to want aggressive treatments and continued medication, tests, and surgeries, even when they know it will not be curative:

> We're in the buckle of the Bible belt, and the belt is expanding. We are an unhealthy section of the country with respect to obesity, sedentary lifestyle, nutrition etc., and so we have a disproportionate burden of chronic illness. While we're speaking about the buckle of the Bible belt we should also mention that we're a very religious state… and with respect to, with respect to traditional religious support from the community, if a patient goes into the hospital and they receive external religious support from their community clergy, those folks… particularly if they have cancer… are much less likely to enter a hospice program and much more likely to die in the hospital, to die in the ICU. It's paradoxical. Chaplain support in the hospital tends to drive down highly technologic care that's not very efficient. So, patients get a more peaceful death and tends to be outpatient or out of the ICU. If the community pastor comes in it's flipped… it's reversed, and typically this works as, you know… "God intends to heal your mother, but we need to leave her on the ventilator until he decides to." So, it's a real challenge. (E7)

According to two (n=2) participants, Tennesseans are known for being very proud and independent, and not wanting to rely on others. Wanting to take care of themselves, their own family, and their own problems. So, to admit they need help, more caregiving support, or more hospice services, is something that is not the norm. This can apply to family members who are currently taking care of someone who is nearing the end of life. They may not want to admit that they need help as one interviewee explained:

> We got a ways to go. I mean, so you know, our health isn't all that good, our rankings aren't all that good, we are proud Tennesseans. Really proud group of people that don't really want to spend down on or end up on Medicaid. They don't think services are really supposed to be for them, so they push those off. And I also think just like every other state in the country, I mean we're growing, we have a growing older population. But I also think they don't like to talk about end of life. (E2)

Living in a death avoidant culture can also impede good end-of-life healthcare. Fear of death can keep people from openly discussing their preferences. Participants agreed that people's inability to talk about death and dying is negatively impacting how end-of-life healthcare is approached. One participant shared their view:

> Sex and death are two topics that families don't talk much about at all. And it makes everybody squirm when you talk about either. And it's hard on both sides. I think if you're the patient who has the disease or the person that has the disease you're um… trying to be strong for a family. And if you're the family, you're trying to be strong for the person. And they're both false views because the other party doesn't need you to be strong for them, they just need you to be there. And so, we take not talking about it as being strong and "you're gonna fight this." Common sense would tell you, if you have a stage 4 pancreatic cancer or an ocular melanoma or any other cancer, your odds of survival are next to zero. So probably worth talking about. (E5)

Talking about death and dying and end-of-life healthcare can be uncomfortable for people. No matter what their age, sex, gender, race, ethnicity, or income level. People just do not want to talk about it. It's uncomfortable, so it is avoided and that perpetuates the problem, and it is a missed opportunity for a less turbulent death.

The Policy Stream

After assessing the current state of end-of-life healthcare in Tennessee during the Tier 1 interviews, participants were asked to provide recommendations for improvements based on their assessment. These recommendations addressed funding, advance directives, caring for the caregiver, education, staffing, and the use of replicable models. Following the recommendations there were discussions around physician-assisted death and assisted-dying legislation that was previously proposed in the state.

Funding

The need for additional funding was one of the first things that came up when participants were asked about needed improvements. The majority (n=7) reported that more funding was a top priority. Participants explained that providing financial resources for needed improvements was an integral part of having more end-of-life healthcare workers, increasing education, providing more ongoing training, having additional end-of-life healthcare options, more access to caregiver support, access to hospice care, and the opportunity for people to obtain residential hospice services:

> Certainly, fund more nurse practitioners, PA's, and physicians. Again, end-of-life care training… that's fellowship programs, and post graduate training. We need to encourage large healthcare systems, and we could certainly make that part of grants or a condition state funded programs such as TennCare, to have POLST [Provider Orders for Life-Sustaining Treatment] forms filled out as a quality measure. Somehow either working with TMA [Tennessee Medical Association] or other sources, we need to make some progress on crosstalk between EHR's [Electronic Health Records] so that once we have the information in the electronic record, it's available to all. And then, you know… try to find a way, either through state funding or lobbying for federal funding, that we can get hospice beds, inpatient beds, funded. Not just built. (E7)
>
> Oh… I'll always go with more funding. If we had more funds, we'd be able to do more stuff. I would love to see healthcare eventually support caregiver services as a paid service, instead of having to come out of pocket. That is probably one of the biggest hurdles that we have to jump through or jump over… or try to fix. (E8)

Reframing Aging

Reframing aging only came up in one of the Tier 1 interviews. Suggestions made by this participant were to provide education, develop programs, and to create an age-friendly environment:

> So, the mission of Reframing Aging is to create an age-friendly environment. And this percolates everywhere. How we design transportation systems, the built environment, how we talk about older folks, how we… where we live, in terms of our residencies. Are we generationally integrated? Things like that are so important and I think that that is probably the way forward. So that we have as a society, an interest in making sure that things are good for all of us as we get older… and we're all going to be aging. (E4)

Providing education referred to the education of healthcare professionals. Educating them on the different needs of the senior population including financial, emotional, mental, physical, and spiritual needs. The second suggestion, to develop programs, would enhance the reframing of aging. According to the respondent, these programs could be done in churches, civic groups, community organizations, or other areas where groups of people gather. These programs would be used to enhance the awareness of the importance of contributions made by members of the senior population.

Advance Directives

Respondents were asked what the state of Tennessee could do to increase the use of advance directives. This question prompted a variety of answers including the need to create awareness (n=6), requiring it (n=3), providing education and training (n=5), and other varying suggestions (n=7). All of the participants (n=10) agreed that something needed to be done to increase advance directive use across the state. Participants felt that planning was important for patients, their families, and the healthcare workers assisting them in their care:

> So, if you don't plan, you take the risk. First of all, I think most people hope that they live in their house for as long as possible and they live to be in their 90s and then they just drop dead… one day, they just don't wake up. They don't even fall down; they just don't wake up. That's probably not gonna happen… I mean, so the idea is to plan for it the best way you can. You don't know when it's gonna happen or whatever, so you plan for it along the way. You have all your documents in place. You make sure everybody knows what it is. And then, you desperately find ways, because I know most people do not want to leave their home, you find ways to make it so you can stay in your home as long as possible. You might need a caregiver or something else like that, but typically what happens is nobody does anything. Nobody talks about it and nobody makes any plans. Nobody has their advanced directive, nobody has their will, and then something happens and now there's mass panic in the family. (E2)

Other interviewees explained how waiting until someone is sick or in the emergency room is the worst time to complete an advance directive:

> I think as far as what we can do about advance directives. That's, that's a different question. Most of what has been studied relates to emergency room urgent decisions, intensive care unit urgent decisions, and that's the worst place. Those are the worst places to have to decide what care you want… the reason to force the advance directives. I think it's much harder to do it in the outpatient area, but I think that's where the future is. For one thing, that's where most of medical care occurs, and that's where the intervention can occur if you want an advance directive before the person gets sick. You want to think about future care… your wishes… and make it easier for those caring for you, including your family who will have to carry those out or make the decisions if you don't. How to do that? I think we're all looking for good models. One is, I guess, to make it a quality measure that the group practice has to adhere to (laughs). Like increasing flu vaccines or pap smears… some things like that. But on the other hand, probably a longer view of this might be to make the care provider, the physician, the nurse practitioner, comfortable in initiating these discussions. It's hard to do on a first visit, and it's usually not necessary unless there's an urgent matter. But over time you get to develop a rapport. (E4)

> Okay so… get them done earlier when they're healthy. Get them done in the primary care clinic. You know, while they're coming in for their regular appointments, ask them their wishes now because there's a lot of healthy people out there who wouldn't want CPR. So, don't wait until they're sick… having to make that decision, or for the family to have to make that decision because the person had a stroke. Get it done early so… when their mind is, they can make their own decision. I think that would be huge. Starting at any age really. (E9)

Creating awareness was suggested by the majority (n=6) of the participants. This could be achieved by having a statewide initiative, including public service announcements. It could also involve State medical boards. This was suggested as a way to gain support for a statewide initiative:

> Do more outreach and awareness about it. Maybe even require that anyone over a certain age has had a conversation about it… you know? If you go into the primary care they ask you if you've been vaccinated. They could ask you if you have ever considered your end-of-life care wishes. I think that would be a reasonable thing. (E1)

> If anybody were to do anything… public service announcements, that make it okay to talk about, it would probably be a good thing. (E6)

Three participants expressed concerns about there not being one consistent advance directive form, that some may be more confusing than others or not be specific enough:

> So, if I were to… if I'm 85 and I have a "do not resuscitate", and unless it's clear, I drop in my apartment and somebody calls the police. They're gonna try to resuscitate me

> unless they know not to. And so, the question is …if they're gonna go through all this trouble to sign these forms…how do you know they're gonna follow them? I mean a lot of this…it's very complicated… but some of it can be simplified, I think. And that is, we need one consistent form so it's very clear. You're talking about end-of-life decisions. So, you need to know whether it needs to be notarized, or if you have to have two witnesses, and you need to understand what the terms mean. There's the form that I think we have on the POLST document is "do you want this…or if you don't want this, do you want this?" And there are places to check. People are getting confused about "If I didn't sign here, do I check this?" This is really important to understand so you want to make the document as simple as possible, and make it easy to understand, where they have to sign, and who has to sign, and what they have to do to make sure that it is followed. (E2)
>
> I mean the discussion I had internally was that "Okay so, why don't we just have one form? Why doesn't everybody work off of one form that everybody agrees to?" And it's a simple, you know, like "Okay, here's the form and then the cover sheet is okay, here's how you fill it out". Once you fill it out, this is where you need to make sure it goes. You know it needs to go to your doctor, your lawyer, your bank, or whatever it is, your friend, spouse. So, that it's all in the right place. (E3)
>
> Most people think they need a notary public or an attorney to have an advance directive. We really need to dumb this down and help people understand it costs three cents to print a piece of paper, and it's a physician's order that you can do anywhere, anytime, with any physician. Be it a nurse practitioner, a PA, or a DDO. Um… and you know, we need to divest people the notion that they need to have a complicated document that costs $2,000 to draw up. (E7)

Participants agreed that simplifying the forms would not only be advantageous for the person filling it out, but also for the people that would need to refer to it or help someone fill it out. This could include doctors, nurses, and other healthcare workers. Respondents agreed that to help this happen, buy-in from the state legislature would be helpful. This would include buy-in from legislators to support the promotion of advance directives, to do a statewide awareness campaign, and to make one consistent form available across the state. One respondent shared:

> One thing that drives me crazy is when we're required to ask if people have an advanced directive and if they say no, we're not required then to actually do one for them. We have to offer it. So, what people do is they'll stack them up in their office and put take one, and then they say, "Yeah we offered an advanced directive." I would like to see a state line initiative to get... because there have been towns that have done an initiative to get everybody to do an advance directive. So, I would like to see a state-wide initiative that says, "Let's get to 100% on this advanced directive thing." Everyone needs one, everyone needs their measles vaccine, they'll push that. This is really just as important and it's even

> maybe even more important, because one in 1,000 people who get measles will die, and that's tragic, and it's totally preventable. Everyone is gonna die eventually and everyone is going to be a potential candidate for a code blue. If we can prevent the ones that don't want it, not only would we be enhancing autonomy for patients who don't want certain things, we'd be saving the system (money). (E3)

There was also a suggestion to tie advanced directives to specific activities:

> When I think about what the state could, or should do, my guess would be it would have to be tied to something that people interact with the state on a routine basis, maybe like a driver's license. That's where we tend to get organ donation talked about. (E5)

Educating people about advance directives was discussed by half (n=5) of the participants. It was recommended that more training for healthcare workers on advance directives was needed. This would include training on how to have the conversation about advanced directives, how to help someone fill one out, and how to make sure someone's advance directive is being followed as intended:

> I think it all goes back to educating people, and you know… having those conversations early… the hard stuff. I think education is so important and I don't know… how do we make sure people understand this? And again, some people are gonna go, "I don't want to talk about this." And that's fine. But this isn't…it's not increasing your life expectancy or decreasing it. It's simply making sure that when there comes a time, which will come for all of us unless you just drop down on the spot, there will come a time where you may not be able to function as well as you used to and you may lose the ability to think through it. And so, you have to remind people that if you get to that point, not only do you need somebody to help pick up that piece, you also want them to follow what your wishes are. And if your wishes again are "I want everything that's possible to keep me alive" then that's fine. One is people should have these advanced directives and I think they should have…um…they should have those conversations (E2)

> I did a whole video on the Tennessee advanced directive. I would like to see that kind of training going out to everybody, like I'll go to the parish nurses, and teach them how to do advanced directive for their congregations. Because I can go to their congregation… and I'll get 60 people to do an advanced directive. But if I teach 10 parish nurses, who then go out and do 60, all of a sudden that's 600. So, I'd like to see that. More education on the Tennessee advanced directive... Not just put it out there, because it is actually a really nice document, but to advocate education and actually do the damn thing. (E3)

Two participants expressed concern that promoting advance directives may not be the State of Tennessee's responsibility. They felt that it may be the responsibility of individual doctors, primary care physicians, emergency room doctors, other healthcare providers, and even clergy:

> I don’t know that um… suggestions about advance directives is necessary owned by the state as much as it should be owned by medical institutions and clergies and families. It’s a hard question of “what should the state do?” I’m not sure they own the problem. (E5)

> Maybe you go to the state and say we need better education in advance directives. The problem with a lot of those things is that they become check boxes. “We need you to do this. The state has mandated it.” “Great. How do we make this happen because I don’t have enough staff? We don’t have time.” That’s where the advance directives in the ER… “Make sure that everybody gets it when they come in.” Does that mean it’s doing well? No. It means somebody knows that there’s a requirement that you have to discuss advance directives in the ER. So, it happens, but it doesn’t necessarily happen well. (E6)

Caring for the Caregiver

Four participants stressed the importance of supporting the caregiver of someone who is at the end-of-life when asked to provide recommendations for improvements in end-of-life healthcare in Tennessee. Improvements in caregiving support included providing financial resources to caregivers:

> We may have to think of how we define family… family may become people who have an interest in caring for that person…in the community, and how we fund people to keep people in the home. Where that we… you know, domiciliary care is such a huge part of the patient specifically with advanced dementia, we may need to think about that a little differently in terms of you know… not finding $10,000 a month to put somebody in a nursing home, but maybe finding $4,000 a month to fund care that supports the family in being able to do that…. We just need to have the political will to do it. (E7)

In addition to financial support, mental and emotional support were discussed:

> I think continued focus on home and community-based services that support the caregivers. Gives them emotional support. Mental support. I hope and trust, but I know that there’s early information to show that it even has very good financial benefits to the healthcare organization. Be that… whether it’s the state or another organization who provides those services. (E4)

Others shared:

> At least in my neck of the woods, is lack of caregiver support. You can expect um… a patient who’s 90 and their loved-one is close to that, and that’s all that they have here, to

> be able to provide the physical care that's required of them. Um… and hospice does not… we don't have the staff to be able to provide 'round the clock care unless they warrant continuous care at that point. Which is typically for uncontrolled symptoms. (E8)
>
> I think it would be awesome for the VA to provide for our hospice patients, in-home 24-hour care. We get that request all the time and it would be just so beneficial for them because… most of the time the wives are just so elderly that they can't take care of them. So, that's why we end up putting them in a nursing home, but if we could supply 24-hour care at home, even if they're not veterans and out in the community, what a big difference that would make. You know? For families to be able to stay home and take care of their loved ones. I think that's a big weakness where we fail, and we could do a lot better with that. You know even the VA we have the home makers program but it's only 15 hours a week in addition to the hospice agencies, and that's just a couple hours a week. So, these elderly people are left on their own. (E9)

Physical and spiritual support were also mentioned as areas of support needed to improve caregiver support. When family caregivers and home caregivers are better supported there are fewer emergency room visits, fewer trips in an ambulance, fewer stays in the hospital, as one participant shared.

Education, Staffing, and Replicable Models

Three additional improvements mentioned included education, more end-of-life healthcare workers, and the need for replicable models. Education included individual awareness around end-of-life healthcare, more education in medical schools on end-of-life healthcare and death and dying, more ongoing training with doctors and other end-of-life healthcare workers on how to have difficult conversations. These areas included both new education and recurrent education:

> Doctors like everybody else…nobody wants to give people bad news…so, you may not give it to them. And then, people are trying to trust their doctor and they probably don't ask a lot of questions. I think somehow, we have to re-train that. Particularly from both the medical perspective and just from citizens. I think people should know, and doctors have to be willing to say…and there's training that has to come with that… to be able to say, "This is what I found, and it doesn't look good." But the same process applies for everything. I mean, you want…I think you really want people to be engaged in discussions about the quality of life, if there's a problem, what is it, and what are the possibilities? I mean we've all known people that have passed away, and it's easier

> to…as difficult as it is, I think sometimes it's easier, if you understand what the path is. Then you know. (E2)
>
> We need to get some more clinical staff trained. You know… more people in the medical field who are interested in specializing and taking extra classes to take care of people at the end of life… Because it is the fastest growing population for sure. I mean, we're all going to be there. And then having the facilities available is huge. (E9)

According to half (n=5) of the participants, more end-of-life healthcare workers are needed.

these workers need to be knowledgeable in varying areas of end-of-life healthcare:

> So, there's a shift that needs to occur to make all physicians, all providers, nurses, nurse practitioners, good palliative care physicians for their own patients. I think that's the exact same thing we've learned in the geriatric model we talked about previously… we need to stop saying 'I'm special. I'm a palliative care doctor. I'm going to fix things.' You can't. You've got to work through… and collaborate with the primary care workforce. They want to work with the palliative care specialists and actually most of the work is not in the hospital. So, that's my future wish for palliative care. (E4)
>
> More doctors. More nurses. I don't know how we'd do that. I don't know what Tennessee can do with that. But definitely more knowledgeable staff. (E10)

Two (n=2) participants suggested more replicable models for end-of-life healthcare. One of the models that was suggested was the VA health system, and that quality measures need to be followed to make the standards the same across the state, in all aspects of end-of-life healthcare:

> We need to follow quality measures that are out there because my concern, being in a community based palliative care, we were one of the first programs in Tennessee to do community based. Now we're seeing a lot of programs pop up but when you actually look at what they are, they're not palliative care. (E1)
>
> I think that we can learn from places like the VA even though it's a different health system. Even though it's a different health system, the VA is particularly putting out more and more information about the benefits of supporting the caregivers and home and community-based services. Homemaker/Home health services is the largest program for community support that the VA has. Can you believe that? Medicare doesn't provide that and as we talked about, Medicaid provides it sparingly. I would say opening that up would be very helpful, and would provide long-term benefits, financial benefits, to the state. (E4)

Physician-Assisted Death Policy

One area of end-of-life policy that is considered highly controversial is legalized physician-assisted death. During the Tier 1 interviews, three questions addressed areas of this important topic. Of the ten end-of-life healthcare experts interviewed, six (n=6) supported physician-assisted death, three (n=3) opposed it, and one (n=1) declined to give an opinion. Interestingly, whether or not the participant was for or against it, they were passionate about their reasoning. They were either very much for it and frustrated that it wasn't legal in Tennessee, or they were very much opposed to it and adamant that it would be horrible for the state to ever legalize it. In addition, two (n=2) of the participants also stated that whether they supported it personally or not, did not mean it aligned with how they felt about it professionally:

> The only thing that the legislation really does is protect the physician… or the family from being... from legal trouble. So therefore, I don't see it as a patient-centric law, it's really protecting other people other than the patient. The patient always has had the right to take their medication in the way they want to. Like I said, I'm a libertarian so I think people should have the right to do what they want with their lives, but I don't want to make it a political thing just because that's my political belief. It's just what's gonna be best for patients and everybody involved and yeah, I am concerned that there would be some people that would be swept up in that, that shouldn't be. Particularly people who don't have capacity to make that decision. Then you're talking about euthanasia. (E3)

Reasons given for those who support physician-assisted death included that it protects the physician, it protects the family, and it protects patient autonomy:

> I'm hoping it becomes legal in all 50… I absolutely do! If you've ever watched someone die with Lou Gehrig's disease, you would absolutely want it legal in all 50 states because they literally drown. We treat our pets better than we do our families. I think that physician-assisted end-of-life should be available everywhere in the country. Period! I think there are certain diagnoses that the death process is so painful and so barbaric, that the only humane thing to do is to give people the option. Whether they choose to accept it or not, it's their personal moral choice, but give them the choice. (E5)

> It's the patient's choice. It's their decision. It's their… they're in charge of their own body… and if that's what they choose to do, that's their choice and I think that it needs to be understood and respected. (E9)

> I'm for it. Like, I think it would be a great thing. I'm not sure about all the stuff we would have to go through to get it, but I do think it would be good for Tennessee to pass that

> though… because people are leaving Tennessee to go like to Oregon, and I feel like if we can bring it home then that would be… it would help. (E10)

For the three (n=3) participants who opposed legalized physician-assisted death, they felt it was wrong to expedite death under any circumstance. They expressed that they would never participate in it and thought it would be hard for other healthcare professionals to participate too. The idea of expediting someone's death with a prescription was different to them than unhooking a ventilator or a feeding tube. The difference was that those devices had been placed there to keep someone alive, so reversing that was not the same as providing something that would cause someone to die:

> I don't personally feel that's appropriate. I am all for… you know, medicating for the purpose of comfort, not ever to expedite death. (E1)

> I'm opposed to it vehemently. I feel that assisted suicide laws, or what are more recently called physician-aid-in-dying laws, are really built on a flawed understanding of what the dying process looks like for patients who have serious illness. I think they're built on a strongman argument that someone is going to die screaming in pain. And it's really a failure of imagination and a failure of palliative care to meet the needs of patients. I think that we can honor the needs of patients with good palliation without… without prematurely ending a life. I am a believer in slippery slope, and that if we do value any life, we value all life. I know that in Oregon there has not been the same type of erosion or, or mission creep of people from… It's not used by a lot of patients, but I think that's going to change as the demographics shift. As our country figures out that we can't pay our way anyway. We have a multi trillion-dollar deficit, and we're not going to have enough workers to support the boomers as they age. Um… and as patients and families bear a larger percentage of the health care burden of cost, I think it's going to get… the financial pressures for somebody to say "You know what? If I ended my life, my family wouldn't have this $30,000 a month bill for the next six months, and I could make things easier on my family." I think economic pressure to check out is going to grow, and so I think that there's a real danger in perceiving a sort of right to die. I think we'll change our healthcare system irrevocably for the worse. (E7)

> I think that to ask somebody to be a part of ending somebody else's life prematurely is not natural. For assisted suicide specifically. Um… that would be very hard for me… and it's not something I would personally participate in. (E8)

During one interview a participant compared the debate around physician-assisted death to the abortion debate. They explained that in Tennessee there are so many pro-life legislators, that even if they agreed with aid-in-dying, they would never support it. It would go against their pro-life stance:

> Our legislature though is ultra conservative, and I think they view this (assisted dying) so close to the woman's right to choose her body, that they can't be complete to their true anti-abortion view and allow this to happen. That's my personal opinion. There's no evidence, but all the conversations I've had are like we have to be 100 percent anti-abortion. Under no circumstances including rape, will we be allowing abortion in Tennessee. And if that's your stance because you say it is sanctity of life, it has to be true at the other end of the spectrum too. And I think they are both incredible shades of grey. We should give our citizens more credit for the right to make their choices. I don't think any woman who gets pregnant is incapable of deciding what is right for her. So, I get really frustrated because I don't think it's pro-life, I think it's pro-birth, and then we don't give a damn about you, is my opinion. But I think the reason so many in the Tennessee legislature are opposed to assisted dying, is they think it will bring into direct fire, their extreme views on abortion. (E5)

Other political views concerning assisted-dying legislation were discussed by two participants who were in support of the policy:

> Well, they (legislators)… don't want to endorse it by making a law that says it's "Okay." To me that's kind of the same thinking of people who don't want their 12-year-old daughters vaccinated for HPV because then they're saying, "Well we're saying it's okay that they have sex" and it's like no... no, we're saying we want to catch them before they're having sex. And presumably, at 12, they're not having sex because once they start, they're gonna get exposed to it and then the vaccine is no good. It's not a perfect analogy, but it's the same kind of thinking. (E3)

> So, when I … as a person I think it, it only makes sense and it should be part of the role, and it fits naturally with recognizing death is a cycle. The challenge comes from a bigger picture. It's one of those power things. It's designed… it's emotional, and sadly in our political process people use their emotions. And it's a really interesting thing because we have a country for which the death penalty is still being done. If you really want to not be hypocritical, you kind of need to be upset about that. If you're not upset about that, you can't really be upset about (assisted dying). So, but anyway, that's pointing out what hypocrisy does… it doesn't work very well. We need to get to a place where the discussion isn't about physician-assisted death, but it's about taking care of people from cradle to grave. Because the moment it (death) becomes a more natural part of the process, and an expected part where we can sit down and talk about how you want to die, there starts to be less of what we have right now which is… we have a big problem. The reason I bring it up is it's such a hot button issue. Um… I'm not sure that's where I'd put my money right now, because I don't know if that… I don't think we're ready to have that conversation, and I don't think we can do it well. I think I along those lines, it's

> wonderful to have some states… you can say, “Look there are some states that have a much healthier approach to a lot of things.” Maybe you want to move there. (E6)

The Politics Stream

A series of questions assessing legislative views around end-of-life healthcare in Tennessee were asked during the Tier 2 interviews which included democratic and republican state senators and representatives from their respective health committees. These questions addressed voting decisions, end-of-life healthcare, end-of-life healthcare policy, voting conflicts, advance directives, caregiver support, and physician-assisted death.

End-of-Life Healthcare Defined by Legislators

Just as during the Tier 1 interviews, Tier 2 participants were asked what they thought of when they heard “end-of-life healthcare.” As was the case during the Tier 1 interviews, participants typically mentioned two or more ideas when answering this question. Aligning with the operational definition of end-of-life healthcare, respondents incorporated the five main concepts: a diagnosis, a timeframe, the type of care a person receives, the location of care, and planning for the future. Timeframe and diagnosis were discussed:

> The last two years of life. If its natural causes, whether it be cancer… you know, not an automobile accident or something like that. There is this time period at end of life that is very intense about healthcare, whether you are 50 years old or 80 or 90 years old, that same proc… we all go through that process. If it’s a natural deterioration until death. Of course, depending on the physical health of the individual when they enter that timeframe, dictates a lot of what take place in that, in the length of time of it. So, the two years is arbitrary. (L1)
>
> The first thing that comes to mind is geriatrics, Alzheimer’s, dementia that sort of stuff. I guess it’s a wide range of things but I’m thinking you know when you know that the end is near. (L7)

Planning for future care and location of care were shared:

> How those approaching death confront the health care system and apparatus in the country or in their community, probably more specifically. I think… homes and hospices and the hospitals and nursing homes... I don't… I don't have a setting in mind. (L2)

The type of care a person receives was also mentioned:

> Well, I think of people that may be receiving hospice care. That's more or less… they know it's end-of-life care. I think of… there's also end-of-life care that you don't know it's gonna be end-of-life. You know, they may be getting care, but don't realize that it really is that imminent… That's end of life care too. You know, there's medical care, there's emotional care, there's physical care. So, I think it's a little bit of everything. (L3)
>
> I think of palliative health care and hospice care. That's what I first think of. I mean, everything from when a person gets diagnosed with some kind of chronic complex, or rare disease. From the day they get diagnosed, to the point that it becomes debilitating, and often leads into hospice and end-of-life. I mean that can last a year, that can last ten years, you may have Alzheimer's for fifteen years. So, I naturally, that's where I naturally… it's the whole continuum. I don't just think the last two weeks of hospice. (L5)

One participant discussed most of the five concepts:

> I think of end-of-life… so, there is either advanced age or a terminal illness. So, that is towards the end of time, and certain decisions have to be made. It also implies that the condition is not curable. That is why it is end-of-life. So, at that time it has to be decided whether the care is going to be given at home, or in the institutional setting… and that depends on the resources, the needs of the person, how dependent are they on care, are they bed ridden, in a wheelchair, and is there support at home? And then certain decisions have to be made about how aggressive the care should be, when does palliative care come in, when does hospice come in? Is there an advanced directive or a living will that outlines what the future holds for this person? Those are the issues I think along the lines of end-of-life care. (L9)

One of the main differences noticed throughout the Tier 2 interviews, was that they were more likely to share a personal experience when asked this question. Nearly half 44% (n=4) of the respondents shared the experience of the death of a close relative when asked this question. Unlike the Tier 1 participants, who were more likely to give a clinical answer of a type of treatment or place where the treatment takes place, goals of care, or time frame, Tier 2 participants were more likely to share a personal experience:

> Hospice. That's the first thing that pops into my head. Yes, my grandfather was put on hospice care. He was already in the nursing home. It was very educational because my mammaw, she fought it for a very long time. Because she interpreted it to me as giving up… "You don't care anymore, it's over." And they sat her down and sat my aunt and

> my dad down, and said, “No, this is what it really means.” (It’s) about comfort level, it’s not giving up, it’s another level of care. And when they educated and helped her with that, she understood. Because that’s not what I thought either. Hospice is like, “Well, we’re done.” And that’s not a fair characterization of it. But that would be one of the times when, when it kind of came close to home. (L4)
>
> I went through this with my mom. My mom passed away in 2018. She had lung cancer, so she went through those stages. We dealt with the palliative care, and the hospice care, and this, and things of that nature… so I’m pretty familiar with this. You know, you want people to die with dignity. (L6)
>
> I think of it as a relatively broad statement in that it can be both geriatric, and then also people my age… our age that have cancer and want to go do some hospice care. Having literally just gone through it with a family member, it’s an interesting process in that what do we do with life… and is life breathing, or is life the ability to get out and enjoy your family and friends, nature? Is it the ability to be cognizance? Is it awareness? (L8)

In a broad sense, Tier 1 and Tier 2 participants agreed on the operational definition of end-of-life healthcare, but in a more specific way, Tier 1 participants were more likely to give a clinical definition and Tier 2 participants were more likely to see end-of-life healthcare as a memory of a personal experience.

Adding Policy to End-of-Life Healthcare

In an attempt to separate how legislators differentiate between end-of-life healthcare and end-of-life healthcare policy, participants were asked what they thought about when they heard the phrase end-of-life healthcare policy. Some of the answers included the supporting of individuals (n=4), hospice access (n=2), access to prescription medicine (n=1), specific legislation and health regulations (n=3), patient rights (n=1), and assisted dying or euthanasia (n=2). One participant said it made them think of advisory councils:

> Well we’ve discussed more the…we’ve had a palliative care bill… the advisory council palliative, I was trying to remember the right word. So, we’re that, we’ve got the Alzheimer’s advisory council. We’ve done, we get updates from the office on aging and their… I forget the exact term, but the music is therapy for the people that… they could use that as a therapy mode. (L3)

It also made them think of general health regulations or general legislation. They were not really specific about which legislation, they just thought of policy that in some way impacts end-of-life healthcare:

> So, when I think of end of life policy, I think more of, of, of, of patient rights. You know… what about patient and family rights? What rights do they have to say, "You know what? We wanna take our family, or we want this for our loved one, or we want to do this instead of the hospitals." Saying "Well, we can't do this because of HIPPA laws, or regulations of our hospitals." So, that's probably what I would lean more towards. (L6)
>
> I'm thinking of helping the aging population sort of navigate through this maze of healthcare… t's a wide range of things that you can do that address the aging population. (L7)

Access to hospice and pain medication were also discussed:

> Well, I directly think of hospice and how we can expand access to those mind-numbing drugs to make the end-of-life process a little more, I guess less painful. (L8)

A surprising response to this question was that three of the participants immediately said assisted suicide or euthanasia when asked about end-of-life healthcare policy:

> That probably makes me feel a little uncomfortable… Uhh, when you start talking about policy of end of life care and depending on what you mean by policy. Are we talking about how we support or not support individuals? How do we allow peaceful death without interfering with that natural process so much? (L1)
>
> The first thing would be euthanasia. The second thing would be quality standards and health regulations to make sure everything is done above board, with the wishes of the individual and the families… and that only qualified individuals and health care providers are offering that type of care. Because those are the ones that know what they are doing. (L4)

Some of the legislators gave answers that reflected a seriousness about end-of-life healthcare improvements, advocacy, and policy reform. Several other legislators weren't dismissive about the topic, but it didn't seem to be something that they were passionate about. Others felt that it was very important, but it was not something that they were up to date on.

Voting Decisions and the Motivations Behind Them

One of the most fascinating parts of the Tier 2 interviews was the discussion around voting decisions. The question asked was "Will you talk to me about what guides or shapes your decisions when you vote on policy?" Some of the strongest driving forces behind voting decisions shared by participants were their morals (n=4), gut feelings (n=3), and principles (n=4). Some legislators (n=3) talked about their "moral compass" and how they use that to guide their voting decisions. They might ask themselves things like "Is this the right thing to do? Is this something I can look at myself in the mirror later and be happy with myself? Is this something that I can vote on a certain way, and then not be ashamed to tell my spouse how I voted?" Legislators typically had several influencing factors that guided their voting decisions, but personal feelings took precedence:

> It's kinda… it's a little bit of everything. It's your moral compass but it's also your life experiences. Whether it's a family member or somebody that you knew that went through something similar. Sometimes it's… you're voting on things and looking at policy on things you never dreamed you would be. (L3)
>
> I run it through a couple of filters probably two or three filters. You've always got to vote your conscience. You just have to. You've gotta run it through your moral compass. You have to be able to go home at night and look at your wife, your children, your family, and feel like you did the right thing. I also feel like I have to run it through the filter of what my district really wants. So, number one I feel like I gotta look through my conscience, then second I do have to look through my district, but the third thing I do real often, if I'm real honest with you, is I remind myself that there is life after politics. So, I really kinda run through those three filters and if I can't get it through my conscious, my district, and my life after politics filter, I probably won't vote for it. (L5)

One participant discussed religious beliefs as part of their personal influence:

> I think it should start with personal values. Why did you run? What did you go to accomplish? What is your wish? So, to me, the first thing that has to be looked upon is will it be pleasing to God…is it biblical or could your mom or God or the Bible approve it? So, is it the right thing to do, let's just say biblical? Number two would be, is it constitutional? Because if you are making the law, or passing legislation, it has to be constitutional. Number three will be what do the people want? They're the ones that elected you. Number four will be where is your heart? Sometimes… it is time to lead

> them… again do you follow the voice of the people, or do you lead the people? So, your question was how do you make a decision? Number one, is it Godly? Number two, is it constitutional? Number three, what do the people want? Number four is it in my heart. Numbers three and four are sometimes in conflict. Am I following the peoples will, or is it Godly? (L9)

Principles were also mentioned as something that guides, or shapes voting decisions. Both personal and political principles came up during the interviews. Personal principles were closely related to moral compass and gut feelings, whereas political principles seemed to be based on the idea of whether or not something is constitutional:

> It's probably a little bit of everything. It can be hard to... hard to separate out all of those things right from one another. So, yeah, I mean I think that there are certain moral commitments and political principles that I have that guide me. I think that I, in evaluating proposed laws try to be pragmatic. And thoughtful at some level… thinking through what the downstream consequences will be. And that's usually… I try to listen to arguments from people who will be affected and do the best I can with the information I've got. At the end of the day, I think it's the job to make people’s lives better. So, if a law will do that, I’ll go out of my way to vote for it. (L2)

There were several other things that legislators said guided or shaped their voting decisions including experiential influences (n=3), future impact (n=2), constituents (n=3), and research (n=4). Experiential influences included both personal experiences and political experiences. For example, if a legislator had a personal experience with opioid abuse with a close friend, they were motivated to advocate for policy reform. Or, if they had a personal experience with kids in foster care, they would be more likely to vote for a policy that supported the foster care system. As far as political experience being a motivator, this would occur when they participated in something as a legislator that influenced their opinion of an issue:

> When there's a nursing home fire, we'll pass new rules about fire… fire systems in nursing homes. Or if there's, a certain kind of health crisis then we'll respond to that. And so, I think that all legislatures are responsive in fact, like that is part of the design. In fairness, the founders intended legislatures to be responsive to what was on people's minds. But if there's any downside, people's minds and what gets attention and news, tends not…it's easier to see the three people that died in the crash over the weekend than

> it is to see the three people that die in different circumstances over the course of a year. (L2)

The future impact that a voting decision could have also influenced two of the legislators, and the impact could be positive or negative. Meaning that whether or not the future impact would be an improvement on the lives of Tennesseans was a factor, but possible negative downstream consequences was also a factor. Legislators said the concern of a voting decision having negative effects on the lives of people in the future played a role in how they voted on policy, even more than whether or not it could have a positive impact. This ties into another variable that influences voting decisions… constituents. This also has two parts; what constituents would want and what constituents would not want. Legislators felt a sense of responsibility to represent the people who had elected them. For instance, one participant said that even if a voting decision seemed to benefit the state as whole, they would not vote for it if it negatively impacted the constituents in their district.

Research was mentioned by 44% (n=4) of the participants. It included using data, listening to arguments from a variety of sources, facts that are presented, and consulting experts. However, only one of the nine legislators said research was the first thing that guides or shapes their voting decision:

> Yeah it's all research. Whatever it is, I want to reach out to whoever the experts are and talk to them. I'm very aware of special interest groups, specifically in this specific subset of legislation and policy. They're trying to figure out who they are representing… Specifically within the health department, health committee rather, the number of doctors that I can call on, the number of executive members within health care companies, is almost limitless. (L8)

Contradicting research was discussed during three (n=3) of the interviews. Legislators felt that depending on what side of an issue you are on you can find supporting evidence. Medical marijuana was used as an example. Some respondents indicated that research says it is great for numerous health conditions, other research refutes that claim or cites it as a gateway drug. This was the same argument many of them had for referring to experts when making a voting decision. This means that it can come back to the legislator's moral compass or gut feeling:

> What I do first is I try to research the issue… then I want to read through the bill to see who's going to be impacted. And once I figure out who is going to be impacted, I reach out to someone that's in that field to understand. It's funny because I am one of the weirder legislators you will ever meet. Because when I first started, I told my wife, "If I can't sleep at night or I can't look you in the face and explain my vote to you or my children, and look myself in the face then I did something wrong." So, I vote my conscious. I try to understand. I can't understand everything. Sometimes I do find out after the fact that, ok maybe I did misread this, or I didn't understand what it was saying at the time. And one last thing… is it the right thing to do? That's the big thing. Is it the right thing to do? (L6)

Each legislator had several different things that shaped or guided their voting decisions. Sometimes they were ranked by importance and other times they were not. One legislator may go by the moral compass, future impact, and research (in that order), while another legislator used research, what their constituents want, and experience (not in any order). Generally, the factors overlap and are intertwined with each other:

> Data comes into play, certainly life experiences come into play, um… moral compass comes into play, research is part of that. You know, you have lobbyist come in, on both sides of the issue, and ask, I try to ask them, depending on how the conversations goes, "what's the opposition saying?" And then when the opposition comes in, does that match up. Am I getting true data or am I getting skewed? That's a good way of doing that. When you ask different parties what their opposition says about this, then you get a better feel of what the legislations dealing with and whether you're getting correct information or not. (L1)
>
> I think it's three things. I think it's experiential, I think it's based on what the constituents want, and also the facts that are presented. Because, I mean, as you can tell from in here, over here this is all budget stuff here. I'm elected to take the time to look at the information that the 700,000 people that I represent don't have the time to do. But, my experience, what the constituents want, and the facts before me are really the three main areas that help me determine how I vote on a particular issue. (L4)

Another respondent shared:

> You know, I feel like I've got my finger on the pulse of the people of my district. So, I base my decision on what's best for the greater good, and of course the first rule of medicine is to do no harm, and that should be the first rule of politics. So, I always do that. I always look at things and I think, "What's gonna put us at the best chance for success? What's gonna benefit the most amount of people with the least amount of risk?" I try to educate myself and sometimes it's just the CliffsNotes version. I try to surround myself with experts from that field that can kinda give me, in layman terms, what's going on. Where do we need to be and what had created this issue and how do we get out of it? Normally I base my decisions off of data, hard facts not emotion, not what's trending… I wanna see evidence. I want to see data that supports what they're saying, I can't debate or compete with individual testimony because each individual's different. (L7)

Conflict with Voting Decisions

Respondents were asked if they had ever been conflicted about a voting decision. Where maybe they had conflicting factors, and they could not decide on an ultimate decision. All of the legislators (n=9) said they had experienced conflict when making a voting decision. The majority (n=7) shared a specific example and two (n=2) said it did not happen often. Two legislators discussed their conflict about gun legislation:

> Sometimes I'm, I probably get a little more conflicted on gun issues. I'm a firm believer of the second amendment right, but it's like, well I… I've never shot a gun. I mean so I wouldn't want me to be able to go out and be able to have a gun without any training. So, thank goodness with the volume of bills that we deal with, there's probably about 600 bills pass a year probably, some of them just change one word. (L3)

> When it comes to guns. I feel the most important thing to me is a background check should be very, very, strong. Then there are loopholes. If you buy a gun at a gun show, you don't have a background check. Or you buy from a friend or a family member, uh you don't have to have a background check… So, that has been a conflict that I have had to confront. I feel that my constituency and my office is relatively small and if you look at my voting record, it is a good record in that I support the second amendment because it's constitutional… and what the people want in my community. People are very strong about guns, (but) I don't know if it pleases God okay? Because he says he's the prince of peace. I know it's constitutionally right, and people want it…and I said you've got to have some background checks, because you can't let crazy people carry a gun. (L9)

One legislator discussed how there are shades of gray, and that "black and white" votes are not always the case:

> So, nothing is black and white down here. You would think occasionally.. you would think occasionally I would have a bill that's absolute black and white. But there is no black and white. Everything has shades of gray and you just kinda gotta come down on what do you think is gonna make the biggest difference for the most people. (L5)

Even when an issue seems simple or straightforward, there can be repercussions that you cannot predict. One legislator gave an example of voting on a bill that would require a registration for boats in Tennessee:

> So, there's a group of people that are proposing that if you own a boat, a houseboat, a speed boat, a sea-doo, or any kind of boat in the state of Tennessee, it's like you have a car. You'd have a basic title on it, so in the event you want to sell it to somebody else, there's some process to say, "Okay, he owned this boat. He sold it to this person." Right now, that's not the case in the state of Tennessee. I can sell you the boat for cash. There's no process to do any of those things. So, they want to introduce a real simple titling process for boats in the state of Tennessee, sure! I have no problem with my conscious… Then all of a sudden my phone blows up from all these people who own all of these boats. But it really comes down to "Does the government really have to regulate everything I do? I have a rowboat, that my grandfather has had, and I been fishing forever and your gonna tell me that I have to go get a title on this silly rowboat that I've had all these years?" (L5)

For the legislators who shared a story about being conflicted about a vote, three (n=3) cited the scheduled March 2020 vote on medical marijuana. They seemed genuinely conflicted about how to vote, and most admitted that they still had not decided. It was one of those issues where the experts and research were contradicting, constituents supported it, and their moral compass was spinning in circles:

> Yeah, the one I have to take tomorrow in fact. And it is right here. That is the medical cannabis bill. That is 71 pages. I took it home with me this weekend, and I already had a meeting with the house sponsor this afternoon, and I'm conflicted about it because I wanna help people that are sick. That have medical issues, and about half of the medical community say, "No don't do it. There's not enough research. It's unsafe. It's a gateway drug… it's all horrible and bad." The other half of the medical community says, "Hey it can help people. There are studies that say it helps people. Let's give it a try. Let's try. We can really help a lot of people." So, now I know how Solomon felt when he came to the baby. Because I'm just sitting here and I wanna make an informed decision. Remember what we talked about… the facts based on experience, which I have no experience with medical cannabis. But thirdly what the constituents want. Now there's a statewide poll that was recently conducted that said 70% of Tennessean's want it. Well

> just because you want it, that doesn't mean how it's set up. How's it's gonna be, under which diagnoses, how it's gonna be dispensed, whose gonna dispense it. What about follow-up, what about liability, what about interactions with other medications? Uh what safeguards would be put in place to make sure that minors don't get a hold of it? I mean there's a lot involved than just waving your wand and saying, "Boom. Here you go." That right there, would be a good example. (L4)
>
> Medical cannabis… I can talk for two hours... I could talk about it on both sides and you can make a great case on both sides. The truth is, there's not a right or wrong. A lot of people think there's truly a right or wrong, there's probably a better or best. (L5)
>
> The first thing that comes to mind is medical marijuana. You know… is it the slippery slope? Is it the gateway drug that leads to other things or is it the natural way of helping chronic pain? I don't know, and I think the water is still muddy. I'm not really sure. I'm conflicted you know. (L7)

Another conflicting voting decision was about an adoption bill and allowing LGBTQ people to adopt:

> On the health committee. there was also some opposition about L-B-Q (LGBTQ)… in private adoptions. Like Agape is church related, and the folks that put children in Agape do not want them going into sex, same sex couples… and this allowed Agape not to place those children there. Where before if they applied and qualified, they could not exempt them. (L1)
>
> Thank goodness not that many times but there are occasionally times that both sides can be right. One that got a lot of press this year was the adoption bill. While you don't wanna prevent somebody that wants to adopt from being able to adopt, you also don't wanna force somebody to um… We are a big enough state we ought to be able to care of all sides of that point of view. I felt like that there was probably already laws in place that protected the religious freedom. So, it was more… I wasn't sure we needed it, but that was conflicting. (L3)

The two (n=2) legislators who had experienced conflict in a voting decision but did not share a specific example, had other thoughts on the topic to share:

> In most bills while you wouldn't know it listening to the media, most bills pass with bipartisan support. I mean but the ones you hear about are the ones that we don't spend that much time on. But it's what gets all the press, because it's more of the social issues or the something that they can say, "really why are you spending all your time on that?" and I'm going, "no we're not." You know it's just the majority of what passes, passes with bipartisan support… and overwhelming support. So, it's just a few things you have to put more thought into. (L3)

> There are not many times I'm conflicted about a vote. Once I do something I know that's what I'm going for… you know because I don't flip flop. When I vote on something, I've done the research and I've tried my best to understand what it is, and I vote my conscious. I vote, well I think, "how would this vote affect the constituents in my district?" That's my number one concern, number two is how does it affect Tennessee as a whole, and that's how I got my decision. (L6)

An Advance Directive Initiative – Support and Opposition

During the Tier 1 interviews, a statewide initiative to promote advance directives was suggested. Participants in Tier 2 were asked what their thoughts were about the legislature's involvement in the suggested initiative. Six (n=6) of the legislators had a positive reaction to a statewide initiative to promote the use of advanced directives. There were recommendations for increasing public awareness through education or even creating policy. A statewide initiative would include appropriating funding, a marketing campaign, and destigmatizing advance directives:

> We could appropriate funding for a marketing campaign with the department of health, talking about it and destigmatizing it. I think that would be something that we could do. Because again, I don't know if other states do it, but you can't mandate something like that. You just can't mandate it. But part I think of health, it's kinda like your first question about hospice, helping to just educate folks it's not evil it's not bad, it's actually a very good thing that you can do, it helps your family. And then the department of health, I would think it would be the department of health that would do it. (L4)

Creating policy around advanced directives included making it mandatory that healthcare professionals not only ask if someone has an advance directive, but actually offer to help them fill one out:

> It is talked about in the sense that every time you go to the hospital… they are asked "do you have an advanced directive", but it's asked in passing… and it is not stressed. And we could do a better job of it, no doubt about it and that would be helpful. So, I think we are reasonable, we could do better, certainly. (L9)

Policy also included adding advanced directive questions to driver’s license forms, renewals, license plate renewals… something that could be done on a statewide level. Other thoughts on advance directive legislation included:

> It will be important to probably introduce some legislation about advance directives… Everything is a learning process. We just have to learn and be able to adapt especially in this new environment we are living in. We’re all on this uncharted territory. We have to adapt to what we’re doing, or we’re gonna have some problems… or be more inventive, or more creative, find a solution. (L6)
>
> I think that a directive or education along the line that make sure that you have power of attorney and you state what you want at the end of life… Do you want to be kept alive on a tube you know… some of that type of stuff? I think we put that off. Folks don’t initiate that. so maybe an encouragement. I know that going to the doctors, and especially when we go to the hospital, they ask that question all the time. (L1)

There were some concerns about the legislature's involvement with the promoting of advanced directives. Three (n=3) of the participants questioned whether or not advanced directives could be mandated through the legislature, and whether or not it was more of a healthcare issue than it was a legislative issue:

> I think there should absolutely be a conversation with your healthcare professional... maybe it’s instead of a legislative mandate. It’s an industry specific and you do it with your primary care physician at 40 and you have that conversation. I think that there should be more knowledge of you know… you need to have an advanced directive. (L8)
>
> I think we could do better. We in the Tennessee legislature, we are conservative, we have libertarians quite a bit, and for that reason we are not going to legislate that we shall have one. That’s not going to pass, so it’s a matter of encouraging it. (L9)

One participant questioned whether healthcare providers and hospitals would encourage advance directives if it would negatively impact them financially:

> All of the healthcare costs you have that last year, six months, accounts for 80% percent or something. I don’t know the exact percentage. And I’ve always been curious… is that the hospitals financial incentive not to encourage them (advance directives), because that’s where they make their money? (L8)

There were also discussions on how this could be a cultural issue in the state, not a legislative issue:

> I think that's a place where sort of both culturally, civically… we could see a lot more work. I'm a lawyer, married to a lawyer and we still didn't have a will that was written or directive DNRs until the birth of our second child. So, I mean… a lot of people don't like to confront the issue, don't like to think about it, but I think that having some greater knowledge about that and greater encouragement… even lawyers are doing wills, to think about that issue as well. Having some way for people to streamline that process, I think... Yeah, I think all that would be very helpful. Because I think… look it makes sense that people when, when your mom is sick, and you haven't had the conversation do you err on the side of not helping? It's just a challenging issue. (L2)

> Most people don't even know what an advance directive is. But no I think that's a good idea it's just another question I think that's something that should be done, because they ask you now do you have a living will or do you have a will you know. Why would you not add one more question to that and then maybe that may spark someone to think "well what is an advance directive" and they can explain that. My mom and I we talked about stuff, so I knew what she wanted. I know what she did and what she didn't want, and how she wanted to be treated. It's a tough conversation to have because nobody wants to talk about death, but hey at the end, whether you like it or not, its gonna happen to all of us. (L6)

Caregiver Support Legislation – Is it Possible?

In response to a suggestion given during the Tier 1 interviews, Tier 2 participants were asked what the State legislature could do to better support family caregivers. Of the participants asked this question (n=6), half (n=3) legislators agreed that Tennessee could definitely do better, and caregiver support needed to be improved. Improvements included that the state needs to invest in good home care, assure good in-home hospice services, and replicate best practices. Suggestions included:

> There are better models around the world… there are models on how countries are managing their healthcare, and it's so much better than ours. They're getting such better results and it has a lot to do with how they approach money and accountability and consumerism and pricing and transparency. You know they do so many things it's just so much better. Our issue in Tennessee is we got seven million people almost and its rural counties and its suburban, urban, and now it's such a quagmire. You can't just start over because you've got incumbent… you've got this hospital here and this home health here and this nursing home here… and it's not easy to say, "okay let's just start over." But if

> we were truly starting over, just me and you siting at a table with the state of Tennessee, we can do better. We have 95 counties… what's everybody need? Then we could have good large regional medical centers. We'd have good hospice and good home care in all these counties… We would have primary care docs. We'd have some good mental health care for folks who really needed it. We could redo it to be so much better, but now we have so much incumbency and money and stuff involve it's hard to break. And Medicare plays a role, and Medicaid plays a role, and all the private insurance are also trying to make money. (L5)

> I would say we need to make sure we are doing everything we can to support our state's caregivers with respite care and support care, and give them the time to go get their hair done and go to the grocery store… have a life… go to church, do everything they want to do. So, they can live a little bit. So, they can actually have the energy and stamina to do it number one. Number two, I'm a big, big, proponent… I'm just home care in general. I just am. If I could change the whole system nationwide, I would put a fortune into home care. I would have the best of the best of the best I would have people that could stay in their home. I don't care what your condition is, right up to the end of your life, we would have robust home care. We set up a hospital bed in your living room. You would take care of folks at home. You would have strong nursing… you know the registered dietician, and respiratory therapists and pharmacist. You got somebody towards the end of their life, and they can live in their home till the very end. (L5)

Participants (n=4) agreed that improving caregiver support comes down to money. First and foremost, increasing caregiver support will take a lot of money and it is a budgetary challenge. The need to expand Medicaid was also discussed:

> Number one we can expand Medicaid… that's the first thing we can do right. Because even in this time right now, that's what's happening. The expansion of Medicaid would help so many people you know, with the testing and the medical cost that they're gonna have. We have so many people that have to deal with medical bills that they're gonna have, that they're not gonna be able to pay for because they're not gonna have a job. Right now, one my issues are that, and I guess because I have a soft spot for elderly people, is nursing homes and long-term care facilities, they're basically trapped. (L6)

Two participants discussed the need for a caregiver pay adjustment. Most caregiving done in-home, at nursing homes, or at long-term care facilities only pays a little over minimum wage:

> I think that we have to do more than we do. The people who provide that work right now make less than $10 an hour, they're basically looking for a new job from the day they start…It's hard work to start with. But then to... you almost have to be looking for another job, because you can't support half a family. Much less a whole life. I think people want to… people work so they can take care of their families, and we've got too

> many places where working doesn’t let you take care of your family. I think if we don’t make that adjustment, we’re going to see continued problems. (L2)
>
> First we know you have to be able to pay people a living wage. I think that how you support them, is you’re able to pay them a living wage… because the people that are doing this they’re doing it because they need the job, but they’re also doing it because they have a passion… because it’s tough. I don’t know if you ever had to wipe a grown person’s butt, but it is tough. (L6)

An additional suggestion was to give employment waivers to people that have non-violent crimes on their record. They cannot work in the caregiving industry if they have a criminal background, but if they are not violent or dangerous individuals, they could possibly work in the caregiving sector:

> We may have to give some people waivers because when you can only pay someone $8.50 (an hour) and they can’t have any criminal background, your pool of employees is so small. It may be that somebody did do something, they did it ten years ago, and they haven’t been in trouble since. They should be allowed to work. There should be certain things they wouldn’t be able to do, maybe if it’s abuse. (L6)

Some of the legislators were unsure about how caregiver support could be improved through the legislature. One participant explained that it would be hard to track. That it is not easy to evaluate home caregivers and their needs, so it would be an overwhelming task to try and take on:

> It's very real. I think probably everybody in the world is one or two steps removed from someone who is spending a fair bit of their time being a caregiver. It's hard, it's such a hard area because it comes in so many different plays. There are nursing homes, there's kids taking care of parents, there's home healthcare, there's home personal care, and it's an area that's very hard to track like public sector, payments, and accountability in a lot of ways. I think both encouraging that on the public’s side, and then also figuring out a way to really advance family leave and sick leave for this particular sort of area. But again, it's challenging. So, what is… some end-of-life care can mean like three days, it could be three years, right? It's a challenge when you think about putting it into budgetary and programmatic terms, though we clearly need to be doing much better than we are on all fronts. (L2)

One legislator expressed that you cannot control family choices. If a family member does not want to be a home caregiver they cannot be forced to do so by the state legislature. They took the caregiver issue presented to them and made it a family issue:

> In other countries, as their population grows older, they become more respected and they become more, more valued… but here unfortunately in this country you see a lot of people that grow old that are lonely, that have nothing, that don’t have a caregiver. Or, you have someone that drops by twice a week and their family’s distant and those that are family, they don’t care. I'm not so sure you can legislate people valuing their grandparents and so on and so forth. Which is sad that you, we would… you know years ago it was just common knowledge that if your grandparents got old you see them actually move back in with their children, or have a house next to them or something like that. There’s been a shift and I don’t know if it’s because there’s more assisted living facilities or nursing homes facilities… but now it seems they contract out to a group that stops by maybe once or twice a week to check on them and help pay bills that sort of thing. (L7)

The Politics Behind Physician-Assisted Death

Participants were asked to share their thoughts about controversial topics in end-of-life healthcare, including physician-assisted death. Of the nine legislators interviewed, four (n=4) supported physician-assisted death and five (n=5) opposed it. Those who supported it, though sometimes with apprehension, shared:

> I just think people should be able to die with dignity. And its… I’m a little, I guess I’m a little conflicted about like um… the assisted part of it. I don’t think anybody should suffer, but I don’t know if someone else should take the life. That’s a case by case basis. (L6)

> I think that we should definitely um have some policy in place that would allow that. (L8)

Another supportive participant discussed how legislators have sometimes compared assisted dying to abortion:

> Well, I think that I don't necessarily put this in the same… I don't put those (abortion and assisted dying) in the exact same box. I think that assisted dying has been at times in that box. I don't think that it's quite in that space… It's hard to find people who are… it's hard to find pro-choice republicans and pro-life democrats at this point. Like, I don't know if this is quite as stark as that. I think that people have some... I think there is some logical,

> reluctance and opposition, no question, but I also think that people kind of think, at least think through a little differently. (L2)

During these conversations it became apparent that there are some policy topics that are very polarizing. Three (n=3) of the legislators who opposed physician-assisted death explained that they are pro-life, not just in regard to abortion, but across the spectrum:

> It can be controversial but at the end, look… I'm very much pro-life, but that's for the entire spectrum. It's from the beginning of life to the end of life. So, I think that it (physician-assisted death) is… it is not a slippery slope, it is a dangerous slide into not valuing and respecting life, if you're not careful. You and I are not the arbiters of death. We're just not, we're not. And I think as a society we need to always try our best to respect all life at all stages. (L4)

One legislator who supported legalized assisted dying said it would need to be altered from what other states have passed. They did not feel it was necessary for a doctor to actually prescribe the medication or for a pharmacist to fill the prescription:

> Well one of my parts on it has been that generally, I started out with the thinking that you as a physician, Hippocratic Oath is that I will not commit, do no harm, pro-life. And taking from there, I felt again… you do see situations where it has been very difficult and painful for people and it is suffering. It is compassion when we say, "can we end the suffering?" and that's understandable. But.. why do you need a physician? Dosages and medications could be given by the state… I don't see a need for a physician really. I think a state needs a health department, dispensary wherever or wherever. After they have completed the paperwork, physician evaluations, that they are of competent mind and a certificate that says the illness is terminal… I think if it were to be done, that would be the model I would be comfortable with rather than a physician (prescribing). I think, because in Tennessee we have a strong pro-life movement, a strong church influence, I don't think our public is ready for it. (L9)

Chapter 5. Discussion

Introduction

The purpose of this study was to examine the perceived quality of end-of-life healthcare in Tennessee, improvements needed, policy recommendations, and political implications. The study was guided by the Multiple-Streams Framework to determine the most important improvements needed in Tennessee's end-of-life healthcare, the policies that could drive those improvements, and the role of politics in end-of-life healthcare policy reform (Kingdon, 2014). In this section, I will summarize the findings of the study and discuss the main themes that emerged from the 19 interviews.

End-of-Life Healthcare – A Societal Concern

This research shows many areas of end-of-life healthcare in Tennessee that need improvement in order to meet the growing need. Participants in this study agreed that with the rapidly growing aging population, Tennessee needs to examine multiple areas of end-of-life healthcare including hospice and palliative care, caregiver support, advance directives, and doctor patient relationships, among others. In November 2013, the APHA issued a policy statement that addressed end-of-life healthcare. In it they recommended that improvements be made to hospice and palliative care policy and financing, advance care planning, education and training for healthcare professionals, coordinated care, pain management improvements, and the increased use of hospice and palliative care. This statement was released because the APHA considered the burden experienced by people at the end-of-life a public health problem (American Public health Association [APHA], 2013; Institute of Medicine of the National Academies, 2015). This statement aligns with the findings of this study and the opinions of the participants.

There were suggestions to address these issues at the local level with community needs assessments, but there were also suggestions that on a national level, Medicare should be restructured, and fee-for-service medicine needs to end. These suggestions show the broad range of the magnitude of this societal problem. A problem, that if we do not address immediately with initiatives or policy, will cause a multitude of crises in the next ten years as the senior population increases dramatically. According to the Institute of Medicine of the National Academies, end-of-life healthcare in the United States is "characterized by fragmentation and inefficiency, inadequate treatment of pain and other distressing symptoms, frequent transitions among care settings, and enormous and growing care responsibilities for families" (Institute of Medicine of the National Academies, 2015, p. 263). There have been proposals to improve end-of-life healthcare since the 1980's that include the greater use of hospice and home care, increasing the use of advance directives, and avoiding futile care in hospital settings. These proposals have been used in an attempt to improve patient care and to reduce spending (Kelley, et al., 2015).

End-of-Life Healthcare Conceptualized

The Operational Definition

There is not a singular universal definition of what end-of-life is, so defining end-of-life healthcare can be challenging. According to the National Cancer Institute, end-of-life care includes support for both patients and their families. These supports can be for social, emotional, spiritual, and physical needs (National Cancer Institute [NCI], 2020). In a broader sense, end-of-life healthcare is specialized care that is given to a person when they are close to dying. There is a general consensus that it ends with the death of a person, but when it begins or what it involves, is hard to determine (Lowey, 2015). It also varies depending on an individual person's needs and personal goals. Though there are numerous definitions of what end-of-life healthcare is, through this research I have come to understand that the operational definition of end-of-life healthcare encompasses five main concepts: a diagnosis, a timeframe, the type of care a person receives, the location of care, and planning for the future. The participants in both tiers of this study included one or more of these five main concepts when discussing what they thought of as end-of-life healthcare.

A Diagnosis

A diagnosis of a terminal illness can include cancer, or any advanced illness that is incurable such as dementia, Alzheimer’s, or a motor neuron disease. Acute conditions that are life-threatening, such as an accident or stroke, are also considered diagnoses for end-of-life healthcare to begin (National Health Service [NHS], 2020). Participants felt that a diagnosis of a condition that was incurable or serious enough to bring about death in a given amount of time, was an integral part of determining when end-of-life healthcare begins.

A Timeframe

Determining a timeframe for end-of-life healthcare was the most difficult of the five concepts to specify. According to the U.S. Federal Code, there are four different survival durations used to specify how long a person has to live. These include less than six months, less than nine months, less than 12 months, and less than 24 months (Hui et al., 2014). This can be problematic in that it makes determining a specific timeframe difficult. Participants who discussed a life expectancy agreed that it can vary based on a patient’s diagnosis, the care they receive, and their goals of care. Generally, when a person is considered to have started receiving end-of-life healthcare is when it is anticipated that death is in the near future (Lowey, 2015).

Type of Care

Hospice care and palliative care were the two most common types of care reported by participants. According to the National Cancer Institute, these two forms of healthcare, along with supportive care, are given to people who have stopped treatments to control or cure their illness (NCI, 2020). Additional types of care can include continued treatment, alternative medicine, or other specialized care that is provided to someone at the end of life (Lowey, 2015). As with determining a timeframe, the type of care a person receives is subjective to that individual and can be influenced by one or more of the other main concepts.

Location of Care

When a person is receiving end-of-life healthcare, there are several typical locations where it can be administered. Participants cited the hospital, the patient's home, a caregiver's home, in a nursing home, a long-term care facility, or in a residential hospice facility. Location was sometimes linked with type of care, goals of care, and timeframe. For instance, if a person is experiencing the last two weeks of their life and they want comfort care at home, they are more likely to be at their own residence or the residence of a caregiver. In comparison, if someone is highly symptomatic and needs medical intervention, they are more likely to be in the hospital.

Planning for the Future

Being given a life-ending diagnosis can cause reflection on values and priorities when it comes to healthcare, and whether or not a person wants quantity or quality to take precedence. It is during the initial life-ending diagnosis that conversations around future treatment or comfort care can be discussed. These conversations are different than advance directive completion or adherence. They are more focused on treatment options for a specific illness or condition. This is an area of healthcare where professionals play an important role in determining whether or not a patient wants aggressive treatment, or if they prefer other options (Karnik & Kanekar, 2016).

Participants in this study felt that planning for the future dictated location of care and type of care.

Goals of Care

An underlying theme of the operational definition of end-of-life healthcare was that it was meant to help a person live out their final days in a way that aligned with their values and goals. Leading institutes of medicine, including the National Cancer Institute in the United States and the National Health Service in the United Kingdom, state that the goal of end-of-life healthcare is to control symptoms and pain so that a patient can be kept as comfortable as possible (NCI, 2020). There is also a goal to help a person live as well as possible until they die (NHS, 2020). This concept was reflected in many of the interviews as participants shared that often, a person's end-of-life healthcare choices are driven by their personal goals of care.

Personal Narratives

One of the only differences between the definition of end-of-life healthcare given by the experts in Tier 1 and the legislators in Tier 2, was the personal narratives shared in Tier 2. Many of the legislators discussed end-of-life healthcare in reference to a personal experience they had been through. This made me realize that a person's personal experience with the death of someone could impact the way they view end-of-life healthcare, in either a positive or negative way. The importance of understanding the operational definition of end-of-life healthcare is that it varies from one person to another. According to the National Institutes of Health (NIH), there is a lack of clarity in the definition of end-of-life that can cause ambiguity and can be a barrier to research (Hui et al., 2012). It could be problematic when proposing relevant healthcare policy if a legislator has limited knowledge on what end-of-life healthcare is. If one person has a completely different concept of what end-of-life healthcare is from another person, it could lead to confusion and therefore inhibit much needed policy reform.

End-of-Life Healthcare Policy

The choices that society makes about its health goals and priorities, and the policies and resources that are used to reach those goals, comprise health policy. When considering end-of-life healthcare policy, the policies reflect the attitudes, values, and beliefs of the people who are creating them, both on a local and national level (Taft & Nanna, 2008). There are a lot of areas of end-of-life healthcare that include policy, for example, advance directives, funding, initiatives, patient rights, and the Health Insurance Portability and Accountability Act (HIPAA). According to the legislators, end-of-life healthcare policy includes access to medicine, access to hospice care, advisory councils, specific legislation, health regulations, supporting individuals, and patient rights. Policy can also include physician-assisted death legislation, and that was mentioned by several legislators when discussing end-of-life healthcare policy. This immediate association could be a hindrance going forward with future research. If legislators correlate end-of-life healthcare policy with assisted dying laws, it could thwart improvements in other areas. No matter what area of end-of-life healthcare policy is being discussed, it is important to remember that policy decisions directly impact patients and the doctors who treat them (Brinkman, 2018).

Meeting the Growing Need

Over the past century, the lifespan in the United States has increased. People are living longer, and the elderly population is growing (Faulkner, 2018). In Tennessee, the population over 65 is expected to increase by 28 percent between 2019 and the year 2030 (Tennessee Commission on Aging and Disability, 2019). This will create its own set of problems that the healthcare industry is not prepared for. Research indicates that as many as 70 percent of baby boomers will need assistance, for an average of three years, as they age. This assistance may be in their own homes, but could require a facility (Norman, 2013). Not only are people living longer, but they are living longer with more chronic diseases like heart disease, obesity, and diabetes.

Aging in Tennessee – The Gaps

Gaps in Preparedness

The majority of Tier 1 participants indicated that Tennessee has gaps in numerous areas of care for the elderly population. These included a lack of providers, gaps in Medicare, lack of facilities, a need for caregivers and support thereof, and an overall lack of funding. Being adequately prepared for the changes in the population predicted by the year 2030 was seen as a significant gap in Tennessee's current end-of-life healthcare system. The lack of funding along with Medicare's limited coverage was discussed openly by participants as one of their biggest concerns pertaining to the senior population.

Gaps in Funding

Medicare does not cover assisted living facilities which can be very expensive for individuals to pay out of pocket. With the percentage of senior-aged Americans on the rise, concerns for their economic stability grows (American Psychological Association [APA], 2010). When you think about end-of-life healthcare, the aging population, and low socioeconomic status altogether, it puts into perspective the increasing importance of improving end-of-life healthcare in Tennessee. One of the key factors in shaping the quality of the lives of older Americans is socioeconomic status. Studies have shown that people with lower socioeconomic status are more likely to suffer from illnesses and die earlier than individuals with higher status (DeNavas-Wait & Proctor, 2014).

Participants expressed concern about the elderly population in Tennessee who are currently, or will in the future be, unable to pay for assistance with end-of-life healthcare needs. There were discussions about the limited number of facilities in the state of Tennessee for the aging population, and how not everyone will be able to take care of themselves at home nor will they have family capable of being caregivers. This will force people to move to assisted living facilities, nursing homes, or retirement communities. The concern is how individuals will be able to pay for this care and whether or not the state of Tennessee will provide financial assistance.

Gaps in Providers for the Elderly Population

The need for geriatric providers is increasing as the senior population increases. Participants indicated that there are not enough providers whether they be geriatric doctors, nurse practitioners, or primary care providers. This will be a vital section of the healthcare industry in the next ten years, as the need for professionals in these fields increases. In order to increase the number of healthcare professionals working in these fields, changes will have to be made to encourage medical students to go into these fields of medicine. One participant, a medical doctor, suggested tuition waivers for students graduating into one of these fields. Another suggestion was to increase the base pay in order to encourage more medical students to pursue careers in these much-needed areas.

Reframing Aging

In 2014, the American Society on Aging and the American Association of Retired Persons (AARP) came together to form the Reframing Aging Initiative. In conjunction with the FrameWorks Institute, research was conducted that showed aging in America is misunderstood, and it leads to discrimination in many areas including healthcare (American Society on Aging [ASA], 2020). Our society, and most around the world, celebrates youth. The stigma around aging or being old, is a cultural and social issue that is deeply imbedded in society. This can lead to a systematic discrimination against older Americans. The Reframing Aging Initiative is fighting to reduce ageism and promote aging as a natural part of life (ASA, 2020; Kluss, n.d.).

Two suggestions that were made by one participant were to provide education and to develop programs to combat ageism. Providing education could be done in a variety of ways, including the education of healthcare professionals. Education on the different needs of the senior population include financial, emotional, mental, physical, and spiritual needs. The other suggestion was to develop programs that would enhance the reframing of aging. These programs could be done in churches, civic groups, community organizations, or other areas where groups of people gather. These programs would be used to enhance the awareness of the importance of contributions made by members of the senior population in an effort to reduce the stigma around aging.

Perceptions of End-of-Life Healthcare Quality

Strengths of End-of-Life Healthcare

The reported strengths of end-of-life healthcare in Tennessee focused on individual hospitals, hospice providers, or geographic locations. There were also brief discussions about the growing interest in hospice and palliative medicine. Participants who reported specific strengths only applied them to their own place of employment, or to a specific experience at a prior place of employment. Others felt that larger metropolitan areas such as Nashville or Memphis had stronger support for dying individuals. The growing interest in end-of-life healthcare referred to the increased use of palliative medicine at larger hospitals and the state’s Palliative Care

Advisory Council. Among the participants there were few strengths discussed, and the lack of strengths aligns with the low national ranking Tennessee currently has in the area of end-of-life healthcare and long-term support services (AARP, 2017).

Weaknesses of End-of-Life Healthcare

Having an ill-prepared end-of-life healthcare system is not something the state of Tennessee can afford to ignore. There were many areas of concern shared during the interviews, of which hospice care, advance directives, and caregiver support will be discussed more specifically in a later section of this chapter. Additional areas of concern included lack of access, the inability for doctors to have difficult conversations with patients, living in a death avoidant culture, lack of providers, stigma around death and dying, insufficient medical school curricula on death and dying, religious influences, lack of funding, ulterior motives in overtreatment, and insufficient patient resources.

Patient Resources Impact Care

A lack of patient resources is an area of end-of-life healthcare that is not directly attributable to the medical personnel or hospital systems, but to the people that they serve in the state of Tennessee. As one participant shared, end-of-life is hard, but it is even harder when you are poor. It is the same for end-of-life healthcare. When a person does not have the resources to pay for residential hospice facilities that are not covered by Medicare, or they do not have the resources or long-term care insurance to cover a long-term care facility, it can make those options impossible.

In 2018, Tennessee had a poverty rate of 15.3%, an increase from 15% in 2017. Tennessee was also one of only nine states to see an increase in its uninsured rate in 2018, which was the second year in a row there was an increase. In 2017 the uninsured rate was 9.5% but increased to 10.1% in 2018 (Bass, 2020; U.S. Census Bureau, 2018). Participants shared a concern that there are many people who do not have savings and they do not have a lot of income. So, to have top notch end-of-life healthcare that is not always going to be covered by the state, the federal government, or by regular health insurance policies, a person has to have money. They have to be able to afford it on their own.

Lack of End-of-Life Healthcare Providers

End-of-life healthcare providers can include geriatric doctors, hospice and palliative care doctors, oncologists, and primary care physicians. In addition, there are physician's assistants, nurse practitioners, nurses, therapists, and a number of other healthcare workers who participate in end-of-life healthcare. Interviewees were open about their concerns for a lack of these providers, and a fear that in some fields, numbers are continuing to decline. According to a study done at Duke University, the declining number of palliative care doctors will not recover for 25 years without policy changes (Kamal, Wolf, Troy, Leff, Dahlin, Rotella, Handzo, Rodgers, & Myers, 2019). The Association of American Medical Colleges urged Congress to remove a cap on residency slots funded by Medicare to help counteract the shortage of physicians, because they project a shortage of up to 122,000 physicians by 2032 (Japsen, 2019). Increasing residency slots could help raise the number of physicians in many fields.

Almost one-third of palliative care doctors report being burned out and 40% are over the age of 56 (Kamal et al., 2019). This is also the case in other areas of end-of-life healthcare. Participants felt that underpaid employees at long-term care facilities and nursing homes are often overworked and have a high tendency for job weariness. There was also concern over the lack of medical students choosing careers in those fields. Several participants, who are affiliated with medical schools, discussed the small number of students who choose to go into primary care or other lower-paying fields. The majority go into sub-specialties like cardiology, oncology, or orthopedics as examples. The most common explanation given was that the salaries are higher. As I will discuss, money was a large influencer in all areas of end-of-life healthcare, including career choices for new doctors. It is imperative that with the growing aging population and the shortage of providers, the state of Tennessee finds ways to address this.

Money's Influence

Throughout the interviews, a recurrent theme in many discussions was the influence of money in end-of-life healthcare. From the influence it has on medical student's profession choice, to the lack of funding, money seems to be impacting all of end-of-life healthcare. As discussed in the previous section, most medical students are choosing to go into a subspecialty and not into primary care because of salary differences. In addition to a higher salary, many students have a high level of student loan debt. The cost of medical school is in the hundreds of thousands of dollars, so participants understood why a young doctor would prefer to go into a subspecialty instead of primary care or geriatrics. One participant recommended waiving student loan debt for graduates who go into primary care or increase the pay they receive.

Lack of funding was talked about throughout the interviews, during discussions about hospice, aging, medical schools, caregiver support, physician-assisted death, Medicare, advance directives, and policy reform. It was also one of the most common responses to the question about the most important things the state of Tennessee can do to improve end-of-life healthcare. The state needs to provide more funding. Participants agreed that more caregiver support, more hospice facilities, additional Medicare benefits, and assistance for the elderly could all be accomplished if there was additional funding.

Ulterior Motives

An area of money's influence that was not expected, was the concept of ulterior motives. During one interviewee's conversation about late referrals to hospice care, the participant mentioned how doctors, who do not want to lose a patient, may delay a hospice referral so they can continue to treat, and therefor bill patients. This was an unexpected response, but a sentiment that was shared by other participants. Late referrals to hospice, which will be discussed in a later section, were sometimes explained by the influence of money. As interviewees mentioned this possibility, it was as if they were ashamed to suggest it. Their voices got quieter and they used facial expressions to make their point clear. I felt as if they wanted it not to be true but believed that it was. The participant's concerns are not an anomaly. In a study of 2,106 doctors composed from the American Medical Association, "most respondents (70.8%) believed that physicians provide unnecessary procedures when they profit from them" (Lyu, et al., 2017, p. 8).

Another area of the interviews where ulterior motives were discussed, was during a question about advance directives. One participant asked why hospitals would promote advance directives when a huge portion of their revenue comes from end-of-life healthcare. Would they not be cutting into their own profits by encouraging patients to have their wishes documented well in advance? If a patient does not have it documented that they would not want to be on life support for two months, that they don't want a feeding tube, or that they do not want to be resuscitated, then the hospital can provide those services. Of all Medicare spending, 25 percent is spent on healthcare the last year of life (Jha, 2018). An important area for future research would be to know more about how often doctors overtreat patients, how often hospitals over treat patients, and whether there is there a connection to advanced directive use or promotion and hospital profit.

Hospice Care in Tennessee

Providing emotional, physical, and spiritual care to patients and their families is the main focus of hospice (National Hospice and Palliative Care Organization [NHPCO], 2020). It is most often provided in the home by a team of individuals that can include, but is not limited to, a physician, nurses, home health aides, social workers, and spiritual advisors. Hospice care can also be provided in a hospital setting, at a nursing or long-term care facility, or in a residential hospice facility. Participants discussed Tennessee's hospice quality, strengths and weakness, and areas that need improvement. Strengths were minimal and were tied specifically to individual hospice organizations, typically a participant's own employer or an organization they were affiliated with. More concerns were shared involving areas of hospice where improvement is needed. The majority of participants agreed that there are significant gaps in the area of hospice care in Tennessee. It was one of the top weaknesses discussed during the interviews. The main areas of weakness included patients being referred too late, a lack of funding, hospice care not being profitable, and at-home hospice not being adequate for every patient.

According to a 2009 study, the most common (62.5%) cause of late hospice referrals were physicians (Adams, et al., 2009). Causes for late hospice referrals include the physician's uncertainty about prognosis, a lack of admission criteria that are standardized, and the physician's discomfort in discussing the patient's prognosis (Spencer, et al., 2017). Physicians sometimes struggle to definitively determine a patient's "six-month prognosis" and have reported delaying hospice discussions for that reason (Spencer et al., 2017). These findings align with the findings of this study. As discussed in the previous section, ulterior motives were also suggested as a barrier to timely hospice referrals. Participants explained that late referrals from physicians can impede the benefits that hospice can provide. Short hospice stays are associated with increased care costs, reduced quality of life, higher rates of needs unmet, and more deaths occurring in the hospital. In contrast, longer hospice stays are shown to have more positive benefits including better pain management, increased care quality, and goals of care are more likely to be met (Kumar, et al., 2017).

According to this research, money is one of the biggest influencers of hospice quality and access. The hospice benefit with Medicare is an outpatient benefit, it is not a residential hospice benefit. It is not room and board. A person who is receiving hospice care at home and has symptoms that cannot be controlled, can be covered for residential hospice services under Medicare, but only until the symptoms are under control. At that point residential hospice is no longer covered. Residential hospice is also covered when a family member who is taking care of someone in hospice needs respite. For a brief time, the person who is receiving hospice care can stay at a residential hospice facility, or in a hospital that has hospice services. Participants explained that residential hospice care includes a visit from a healthcare worker two to three times a week. They do not visit the home daily, nor do they stay there all day or night. Also, Medicare does not cover other caregiver services like cooking and cleaning when someone is in hospice. At-home hospice is not adequate for every person because, as participants agreed, for some patients there is not enough at-home support.

According to two participants, one of the reasons there are not more residential hospice facilities is that they have a hard time staying full. Medicare does not cover it as a permanent arrangement. Since most people cannot afford to pay out of pocket for these kinds of services, the beds are sometimes left empty, and they end up closing down. If they are able to keep the beds full, the reimbursement rates are so low that there is not enough money to run a high-quality residential hospice facility. It is just not profitable. This is why other options like long-term care facilities and nursing homes offer hospice care too, but because of the reimbursement rates being so low, they have now switched over to taking in more rehabilitation patients, such as people who have just had surgery and need to stay somewhere for a longer period of time. Medicare, TennCare, and private insurance will reimburse for those services at a much higher rate than they do for hospice care. So, for someone to stay in a residential hospice facility, if they have their symptoms under control and there is not a need for respite care, the family has to pay out of pocket.

Having Difficult Conversations

Physician-patient communication about death and dying is lacking in the United States. According to the 2015 *Dying in America* report, it is one of the most important areas in need of improvement for patients who are approaching the end-of-life (Institute of Medicine of the National Academies, 2015). Healthcare providers from different backgrounds, varying specialties, and of all ages, find it challenging to have conversations about end-of-life healthcare with their patients (Baruchin, 2016). It is important to understand the significance a conversation between a doctor and his or her patient can have on health outcomes. Research shows that end-of-life conversations are predictive of earlier hospice referrals, higher patient-family satisfaction, and fewer treatments that reduce quality of life. Other links include less acute-based hospital stays, intensive care unit visits, and more use of hospice (Johnson, 2018). Not all patient-doctor conversations about end-of-life care leads to fewer treatments, as some patients may elect continued intervention. The most important idea is that having these conversations can lead to a greater understanding of a patient’s preferred care and their personal values.

Participants shared their thoughts on why doctors find it difficult to have these conversations and four main ideas emerged. The first was that doctors do not want to make their patient lose hope. If a physician tells a patient that his or her treatment has failed then the patient may decide to give up emotionally and mentally. Secondly, doctors are not trained to have these types of conversations. This starts in medical school when students are not given instruction on how to have difficult conversations. They are not taught how to talk to someone about a terminal diagnosis, goals of care, or future healthcare options. Third, difficult conversations are uncomfortable. Doctors are trained to be objective and detached and not to get emotionally involved. Having end-of-life conversations are personal and can be emotional.

The last idea shared by participants was that having difficult conversations, particularly ones that involve terminal diagnoses, can make a physician feel like they have failed a patient or that they are giving up on them. According to Tamar Vesel, MD, Tufts Medical Center's chief of palliative medicine, "Patients need to know what is happening to them, so they can plan and doctors need to see illness and death as an opportunity for societal and personal growth, instead of a societal and personal failure" (Paturel, 2018, p. 1). To tell a patient that their cancer is not curable, or they have ALS can be very difficult, but it is an opportunity for doctor-patient growth. As a death avoidant society, talking about death and dying is not just a problem between the doctor and a patient. It is embedded in all of society, but in the area of end-of-life healthcare it is so important to have these conversations and to start normalizing it.

There is an increase in the number of organizations and programs aimed at improving doctor-patient conversation. They are meant to improve physician's communication skills on topics such as goals of care. These programs include The Conversation Project and VitalTalk (Mor, 2017; Paturel, 2019). Studies show that more physicians are starting to see end-of-life conversations as being as important as any device or drug (Paturel, 2019). The states of West Virginia, California, and Pennsylvania have introduced initiatives or funded organizations to improve doctor-patient communication, specifically in areas of prognosis and options for treatment (Hostetter & Klein, 2020). Tennessee needs to examine replicable models on communication, such as Oncotalk, a program developed by researchers at Duke, the University of Washington, and the University of Pittsburgh. It is a program that trains oncology fellows ways to communicate bad news (Hostetter & Klein, 2020). In the 2015 *Dying in America* report, it is recommended that all medical schools and nursing programs incorporate palliative care and end-of-life training into the curriculum, which would include teaching communication skills to all students and residents (Institute of Medicine of the National Academies, 2015). According to participants, this type of training is offered, but the amount and type vary across programs.

Medical School Education on Death and Dying

The importance of learning about end-of-life healthcare and understanding the process of death and dying, is more important than it ever has been. This is because of the aging population, the increase in incidences of chronic illness and cancer, and a longer life expectancy (Bickel-Swensen, 2007). In less than one century, the life expectancy in the United States has risen from 47 to 78 years. In addition, the population over 90 years old is the population’s fastest growing group (Institute of Medicine of the National Academies, 2015). Varying approaches to teaching end-of life care have been used by medical schools in the past but are typically allocated minimum classroom time and clinical exposures are random (Horowitz, et al., 2013). This is not acceptable. Participants stressed the importance of increasing the training but felt that improvements were being made, though slower than what is needed.

According to Tier 1 participants, doctors are trained to fix things. They are trained to save lives and make people feel better. They learn how to set a broken bone, help a patient reduce their blood pressure, put stitches in a cut, and how to do any number of patient-centered interventions with the intent of producing a positive outcome. What they are not taught very much about is how to help a patient die well or help them make the decision to discontinue treatment or stop taking a medication that is keeping them alive. So, for medical schools to train their doctors to embrace death and dying and learn about end-of-life healthcare and the importance of it, almost negates what they are trying to teach, which is to preserve life at all cost. According to participants, physicians usually see death as a failure. There is an idea that prolonging life is the ultimate goal, not giving up. Therefore, end-of-life healthcare training is not a priority. It is not something that is deemed as important as other areas of medicine.

Stigma around Hospice and Palliative Care

Stigma has been defined by sociologist Erving Goffman in terms of attributes that are deeply discrediting and undesirable (Goffman, 1990). The stigma around hospice and palliative care fits that definition completely. According to participants, sometimes when a doctor mentions hospice to a patient, even if they have exhausted all treatment options, the patient is most likely to think the doctor is going to just let them die. Family members can feel the same way. They can feel that the doctor, the medical team, or the hospital is just giving up. Hospice can be a scary word for most people. It brings about thoughts of stopping treatment, taking away medicine, withholding food and water, and neglect. These ideas come from years of assumptions and misinterpretations of the function of hospice care. Participants indicated that this could contribute to why hospice is referred so late, or conversations about it are hard to have. Hospice care is so much more than just letting someone die. It is quality, comfort, and respecting a patient's goals of how they want the end of their life to be. Until we break the stigma around hospice, it will be difficult to increase its use.

The associated stigma of palliative care includes hopelessness, death, and dependency (Zimmermann, et al., 2016). Studies have shown that the term “palliative care” brings about more negative perceptions, than does the term “supportive care”. Not just with patients, but with physicians and the patient’s family (Zimmerman et al., 2016). The avoidance of terms like “palliative” and “hospice” reflect the associated stigma, which relates to the societal attitude about death (Zimmerman & Rodin, 2004). We live in a death avoidant culture. This negatively impacts end-of-life healthcare because it keeps people and healthcare providers from being adequately prepared for end-of-life issues.

Religious Influences

Another area of influence reported by respondents was religion. According to two participants, religious influence can sometimes be a barrier to good end-of-life healthcare because it can keep a person from accepting death and preparing for the process of dying. They also shared that people who are highly religious are much less likely to accept hospice referrals or hospice treatment. They are more likely to want aggressive treatment, even when they know it is not curative. A study published in 2009 showed that most patients with advanced cancer used religion to cope with their illness, and the more that positive religious coping was used, the more life-prolonging medical care they chose to receive (Phelps, et al., 2009).

It is important to understand the influence of religion when doctors have end-of-life conversations with their patients because faith was given as the second most important factor when deciding on a treatment plan (Silvestri, et al., 2003). Recommendations from the physician was the most important (Silvestri et al., 2003). This shows the influence religious beliefs can have on a patient’s treatment decisions. In a survey of 1,006 people, 68 percent said their medical decisions would be guided by their religious beliefs if they were facing death, and 57%

believed that even if their doctor said no medical treatment could help, God could heal them (Jacobs, et al., 2008).

Family members can also express these characteristics when it comes to religiosity. When a family member is in a coma or on life support and is dying, the family is less likely to take them off life support, unhook a ventilator, or discontinue a feeding tube if they are religious, according to participants. A patient's family can also refer to religious beliefs when deciding about treatment options. Religiosity has been associated with a higher preference for the use of ventilators, heroic end-of-life measures, cardiopulmonary resuscitation (True, et al., 2005).

Influences on Policy Reform

Numerous factors can influence public policies. Factors include economic conditions, public opinion, interest groups, public organizations, and technological change (Gittell, et al., 2013). According to this research, there are three main influences on policy reform in the state: the current political climate, the perception of need, and public demand. The political climate can include which party holds the majority in the House or the Senate, whether or not there is a democratic or republican governor, and what is happening on a national level. It could also be historical events like what we are experiencing now, the COVID-19 pandemic and the Black Lives Matter movement, both of which had altered the current political climate in this country drastically over the last six months.

Another influence on policy is perception of need. When this was discussed during the interviews it was explained to me that policy reform happens, when the perceived need is great enough. This perception of need could be created by advocacy groups, television commercials, blogs, podcasts, pamphlets, word of mouth, and many other ways. It could also be created by the state legislature seeing a need. Seeing an increase in hospital stays for the elderly population for example, an increase in the use of TennCare, or an increase in requests for caregiver assistance. When the perceived need is high enough, it can push policy reform. When the state legislature sees the need at a high enough level, then policy reform will take place.

The third influence is public demand. Participants indicated that even if the political climate is not perfect, or the perception of need has not reached the level that it needs to, if there is public demand, then policy reform can happen. Support can also be garnered through social media, the newspaper, and television stations. Social media is a huge avenue for creating public demand to influence policy reform. There are a wide variety of influences affecting policy reform, so changes to public policy often happen slowly.

End-of-Life Issues Addressed with Policy Makers

After the completion of the Tier 1 interviews, two main areas of end-of-life healthcare stood out as areas to be addressed with state legislators during the Tier 2 interviews. Both advance directives and caregiver support were determined to be two issues that could be addressed with policy in a timely manner. Both are both discussed below.

Advance Directives

As a country, we celebrate having control of most aspects of our daily lives. Where we live, who we marry, where we work, etc. Unfortunately, one area where most Americans abandon that control, is at the end-of-life. The easiest way to maintain control of healthcare decisions when incapacitated is with an advance directive. Advance directives are written instructions of a person’s healthcare choices for what they would, or would not want, in the event that they are not able to speak for themselves. It seems like everyone would have one of these important documents, but only around a third of adults over the age of 18 have completed one (Yadav, et al., 2017). Increasing this percentage should become part of the public health agenda, not only in Tennessee but across America, because the treatments people receive at the end of life, are very often different than the treatments they would have chosen (Yadav et al., 2017).

According to participants in this study, there are many benefits to having an advance directive, or other similar end-of-life document, establishing individual preferences in the event of incapacitation. These benefits include, but are not limited to, respecting patient autonomy, eliminating unwanted treatment, reduction in cost from unwanted medical services, reduction in burden of family making decisions for the patient, and less suffering for patients and their caregivers. People who have completed an advance directive are also less likely to die in the hospital. These findings are supported in the literature as benefits to having an advance directive on record (Hogan, et al., 2001; Silveira, et al., 2010)

Barriers to Their Use

The completion of an advance directive can be influenced by many factors. Some people simply feel they are too young and healthy to need one or they may find the forms confusing and time-consuming. People have also reported not knowing about advance directives or where to get one (Morhaim & Pollack, 2013). Several participants in this study felt that death avoidance played a significant role in whether or not someone completed an advance directive. When a person is uncomfortable discussing end-of-life healthcare preferences, they find the conversation about advance directives off putting. Completion can also be hindered by the lack of doctor-patient communication. Research shows that people prefer to get advance directive information from their doctor, which means that providers play an integral part in completion of these documents (Morhaim & Pollack, 2013).

Increasing Their Use

To increase the percentage of adults who have an advance directive, several suggestions were offered during the interviews. These recommendations included creating awareness, requiring it, and providing education and training about them to individuals and healthcare workers. Creating awareness could be done through the legislature with a statewide initiative to promote their use. Policy could also be used to provide education and training on how to complete an advance directive and have the conversations needed to initiate the conversation. At Vanderbilt University Medical Center, they initiated the "Got Yours" campaign to encourage patients and employees to complete an advance directive. The campaign is being used to remind people about the importance of having an advance directive, and how it benefits, not only the person filling it out, but their family and healthcare provider (Batcheldor, 2016). Other similar initiatives have included the *Conversations of a Lifetime* initiative which encourages grown adults to have end-of-life conversations with their aging parents, and the Tennessee-based initiative *Advance Directives TN*. This initiative was launched by Honoring Choices Tennessee in the Northeast region of the state (Honoring Choices TN, 2017). These may be great models for a statewide initiative that could be promoted through the state legislature.

Another way to create awareness is to make it okay to talk about. Again, we get into the idea of death avoidance and having difficult conversations, but the more people hear about advanced directives, the more normal they become. Several participants recommended making an advance directive option available to people when they renew their driver's license, get a new license, or ID. When they are asked about whether they would like to be an organ donor, they could also be asked if they would like information on advance directives. Then have those forms available at the motor vehicle's office. If we can ask about organ donation when someone goes to get their license renewed, certainly we can ask about advance directives.

A lack of education on advanced directives is also a hindrance to having them filled out. Not only on the part of the individual filling one out, but also on the part of the healthcare workers who ask about having one and assist in filling them out. The literature supports what this research has shown. In a study published in the American Journal of Public Health, researchers share that "the role of advance directives should be part of medical education and training and incorporated as an aspect of cultural competency" (Morhaim & Pollack, 2013, p. 9). Until people are more informed about what an advance directive is, where to access one, how to fill it out, and who to talk to about them, the percentage of people having one will not increase. In addition, it is just as important to make sure that all healthcare providers are comfortable having these conversations with their patients and are trained on all aspects of advance directives and their use.

What Can the Legislature Do?

The importance of state and federal provisions for advance directives, and advance care planning, is continuing to grow (Epstein, Volandes, & O'Reilly, 2011). When discussing policies that could increase the use of advance directives in Tennessee, several of the legislators had a positive response to promoting some sort of statewide initiative. An initiative could include a campaign similar to the public service announcements used to reduce drunk driving and texting and driving. This could help socially normalize the use of advance directives. There were also recommendations for increasing public awareness through education or by creating policy. A statewide initiative could include appropriating funding, developing a marketing campaign, and/or destigmatizing advance directives. Creating policy around advanced directives could include making it mandatory that healthcare professionals not only ask if someone has an advance directive, but that they go a step further and actually encourage them to fill one out.

Policy could also include adding advanced directive questions to driver's license forms, as suggested by several of the Tier 1 participants.

There were some concerns about the legislature's involvement with the promoting of advanced directives. It was a question of whether or not advanced directives could or should be mandated through the legislature, and whether or not it was more of a healthcare issue. The underlying question was, whose responsibility is it and is it something that can be mandated through the state government? Some felt that it is the responsibility of the healthcare industry. It could even be the responsibility of the individual person. The literature suggests that legislators and the healthcare industry should both play a major role in the increase of advance directive use, but that it is also an individual's responsibility to take full advantage of all of their options (Morhaim & Pollack, 2013).

There were also discussions on how this could be a cultural issue in the state, not a legislative one. Several legislators felt that people not wanting to fill out an advanced directive was a consequence of living in a death avoidant society. The United States is considered a death avoidant society in which people do not like to talk or think about death. This can have many harmful consequences including the reluctance to talk about end-of-life choices (Hess, 2018). The consensus was that there is nothing that the state legislature can do to change that. Though the legislators had pros and cons to the suggestion of an advance directive initiative or legislature-involved protocol, most seemed unsure as to how to go about initiating one. The majority felt that it was a very important concern, and one that needed to be addressed, but were not sure if the legislature was responsible. That it was more of the healthcare industry's responsibility and that it should be done between a patient and their doctor, not necessarily promoted by the state legislature.

Caregiver Support

Caregivers for people who are at home during their end of life, are most commonly family members. They can include a spouse, children, siblings, or grandchildren, among others. For the purpose of this research, the family caregiver was the focus of caregiver support in Tennessee. Family caregiving is one of the main reasons people are able to stay at home while receiving end-of-life care. This is of benefit to the dying individual but can come at a high price for the caregiver and the caregiver's family. Caregiving can be emotionally, physically, mentally, and financially exhausting. One participant shared with me that they had a patient whose caregiver ended up being hospitalized due to exhaustion. They also shared a story of a caregiver who committed suicide while caring for a loved one. They explained that when you have a patient who is at home receiving hospice or other end-of-life healthcare, you actually have two patients. The person who is dying, and their caregiver.

In 2009, family caregiver support in the United States was valued at $450 billion dollars (Feinberg, et al., 2019). Research suggests that this will be hard to sustain with people living longer, and their grown children working later in life, and that the potential loss of family caregivers would increase the burden on Medicare and Medicaid (Administration for Community Living [ACL], 2020). Caregiver support was not asked about specifically during the Tier 1 interviews, but it was a topic that came up when participants answered different questions. Participants felt that it was an important area of end-of-life healthcare that needs to be given more attention, both in the community and in the legislature.

Caregiving is underfunded, and at times, an underappreciated task taken on by family members when a loved one is dying at home. One participant called family caregivers the unsung heroes of end-of-life healthcare. By trying to take care of themselves, trying to work, and trying to be a caregiver for someone who is dying, they can sometimes burn out. This type of burnout has been given a name: caregiver syndrome. According to the literature, many family members who take on the role of caregiver do not realize the amount of physical and emotional work they will be required to do (Farmer, 2020). This sentiment was shared by participants who explained that there are not always family members available to take on caregiving on a full-time basis and end-of-life caregiving can go on for weeks, months, or even years.

Recommendations for Improvement

According to participants, needed improvements for caregiving included providing more funding, more mental and emotional support, more physical support, and even additional spiritual support. The most important of these depends on the individual needs of the caregiver. From this research, it appears that providing more financial resources is the most important change to make. This could in turn decrease the need for other areas of suggested improvements. One participant explained that the state could provide financial support for a family member to stay home and take care of a loved one, instead of paying twice that amount to a nursing home.

Addressing the needs of at-home caregivers can seem insurmountable, and there did not seem to be one unified solution from the participants. The main takeaway was that we have to make sure we are taking care of the caregiver, so that dying individuals can remain at home. We need to expand how we support caregivers, by expanding options available for at-home care and make those options available for a longer period of time. This may be best achieved through a joint effort of healthcare providers and policy makers. In the July 2016 edition of *Preventing Chronic Disease Public Health Research, Practice, and Policy* journal, a call to preventive action on this important issue was published. In it the authors wrote “The health and well-being of our informal caregivers is in many ways the backbone of our system of care. Those of us in caring professions have both a moral and ethical responsibility to support these hardworking caregivers. Meanwhile, those in policy-making positions have a responsibility to create policies and systems that enable caregivers to perform their duties without compromising their own health and economic well-being" (Hoffman & Zucker, 2016, p. 1).

Caregiver strain can involve physical decline including fatigue and overall poor general health, and the emotional impact can include depression, stress, and anxiety (Finley, 2018). One agency that attempts so support caregivers is the National Family Caregiver Support Program. According to its website it "provides grants to states and territories to fund various supports that help family and informal caregivers care for older adults in their homes for as long as possible" (ACL, 2020). They work together with state and community-based organizations to assist them with coordinated care. According to one participant, these resources however are limited, and families may have to wait to receive assistance.

What Can the Legislature Do?

Some of the legislators agreed that Tennessee could definitely do better in the area of caregiver support, and that improvements needed to be made. Suggestions were that Tennessee could provide funding to improve in-home care, in-home hospice services, and also replicate best practices. Participants also agreed that, for the most part, that improving caregiver support comes down to funding. First and foremost, increasing caregiver support will take a lot of money and that it is a budgetary challenge. As it was with the discussion about an advance directive initiative, I got the feeling that when asked about caregiver support, most of the legislators were unsure what could be done. One participant said it would be difficult to determine the actual need because it was hard to track. It did not seem to be something most of the legislators had given much thought to, unless they had recently experienced the death of someone, though they all agreed it was certainly a concern.

The Influence of Politics

Motivations Behind Voting Decisions

State legislators are continually asked to make decisions. They have to decide what issues they want to address, how they want to vote on specific policy, and which side of an issue to support. Understanding their decision-making process, and what influences those decisions, is paramount to understanding the impact it can have on end-of-life healthcare policy. According to the National Council for the Social Studies, legislators typically use three considerations when deciding on policy (NCSS, 2020). First they use their head to determine if it is good policy and would their constituents agree. Does the policy make sense? Secondly they use their heart. This is especially important when voting on issues that are controversial or considered “hot-button” issues. They typically rely on personal stories or experiences and in the end, they vote the way they feel is right. The third consideration is health. Not physical heath, but their political health. Unfortunately, a lot of voting decisions are made with the knowledge that a wrong vote can hamper reelection chances (NCSS, 2020). Legislators typically want to get reelected, so that is something they consider when voting on policy. This can be important, particularly when the political climate is uneasy.

The literature supports the findings of this research, which showed that legislators use a variety of considerations when deciding on a voting decision (NCSS, 2020). The motivations most commonly reported in this study included morals or the “moral compass”, gut feelings, principles, personal and political experiences, what their constituents would want, the future impact the policy could have, and research. Most of the participants reported using several of these considerations, and they typically had an unofficial ranking of what considerations were most important. Religious beliefs were mentioned as a guiding force, and though only one legislator specifically listed religion as a main factor that impacted their voting decisions, other legislators referenced religious beliefs in their answers.

The "Moral Compass" and Gut Feelings

Legislators talked about voting their conscience, which means that they ignore practical politics and focus on their moral values. This finding aligns with the literature. Research has shown that moral convictions are solid political cues and can be based on moral assessments that occur rather quickly (Bloom, 2013). In a study published in *American Politics Research*, it was concluded that moral convictions in political attitudes are related to attitude strength, increased involvement, and extremity, and that it is the case for both opponents and supporters of a policy (Bloom, 2013). I understand that we all make decisions based on a moral compass, or some sort of gut feeling, but in the state legislature I would have expected that to play a minimal role in a legislator's voting decision on policy. The one question that I keep asking myself is, "Is there a way to separate a legislator's moral compass or gut feelings from their professional responsibilities, and their duty to represent their constituent's needs?"

Personal and Political Principles

One legislator explained to me that they decide on a voting decision by whether or not what they are voting for is constitutional. They also explained that sometimes personal and political principles can clash with each other. Something could be constitutional, therefore in alignment with their political principles, but could be something that they do not agree with on a personal level, so it goes against their personal principles. When asked to rank which was more important, they would say that it would depend on that particular piece of legislation. It would depend on how strongly they felt about it on a personal level. That is when their gut feelings or moral compass would be considered when making a final decision on a policy.

Experiential Influence

There were several other things that legislators said guided or shaped their voting decisions including experiential influences, future impact, constituents, and research: Just like principles, experiences included both personal experiences and political experiences. Personal experiences seemed to be one of the driving forces behind a legislator's choice of policy focus also. I have always been fascinated with motivation, and experience seems to be a powerful motivation for people in general. For example, if a legislator had a personal experience with opioid abuse with a close friend, they were motivated to advocate for policy reform. Or if they had a personal experience with children in foster care, they would be more likely to vote for a policy that supported the foster care system. This is important to consider because if a legislator does not have a biographical connection to a particular policy, it may impede their ability to connect to it on a personal level. Life experiences matter when it comes to policy reform, and whether or not a policy aligns with a legislator's life experiences can influence their voting decision. As far as political experience being a motivator, this would occur when they participated in something as a legislator that influenced their opinion of an issue.

Future Impact and Constituents

The future impact that a voting decision could have also influenced some of the legislators. The impact could be positive or negative. Meaning that whether or not the future impact would be an improvement on the lives of Tennesseans was a factor, but possible negative downstream consequences were also a factor. Legislators said the concern of a voting decision having negative effects on the lives of people in the future played a role in how they voted on policy, even more than whether or not it could have a positive impact. This ties into another variable that influences voting decisions, constituents. This also has two parts; what constituents would want and what constituents would not want. Legislators felt a sense of responsibility to represent the people who had elected them. For instance, one of the participants said that even if a voting decision seemed to benefit the state as whole, they would not vote for it if it negatively impacted the constituents in his or her district.

Research

For this study, research included data, listening to arguments from both sides, facts that are presented, and consulting experts. Only one of the nine legislators interviewed said research was the first thing that guides or shapes their voting decisions. Though most did say that research plays a role, it was not as prominent as expected. With that being said, research does influence voting decisions, but since research can be contradicting at times, the decision ultimately comes back to a gut feeling. Legislators felt that depending on what side of an issue you are on you can find supporting research. Medical marijuana was used as an example by several legislators. They shared that some research says it is great for numerous health conditions, other research refutes that claim, or cites it as a gateway drug. This was the same argument for listening to experts for advice. Two respected experts in a field can give completely different opinions on the same topic. This means that since research can be contradicting, how they vote on a policy can be influenced by the legislator’s moral compass or gut feeling.

Voting Decision Conflict

Conflicts over a voting decision have been reported to arise from uncertainty of the issue, contradicting data from the experts, or from inner conflict that is based on personal and political preferences. Participants expressed these concerns when asked whether or not they had ever been conflicted about a voting decision. The findings of this research are supported by the literature which states that there are two sets of reasons why legislators may be conflicted about a vote. The first is technical complexity and the second is political complexity (O'Donovan, et al., 2016). Technical complexity includes ambiguous evidence and uncertainty about causal connections. Political complexity is focused on politics of party loyalty, the preference of constituents, and ideology (O'Donovan et al., 2016). When conflicted about a voting decision, participants shared that they rely on, as was discussed in the previous section, their motivating factors, and other considerations. As one participant shared, there are rarely voting decisions that are purely "black and white".

Physician-Assisted Death Explored

The debate over physician-assisted death, or what is sometimes referred to as medical aid in dying, has been contentious for a long time (Friesen, 2020). However, the increase in support has been rising across the country as more states continue to legalize the practice. According to the May 2020 Gallup Poll Social Survey, nearly three out of four (74%) people in the United States agree that "When a person has a disease that cannot be cured, doctors should be allowed by law to end the patient's life by some painless means if the patient and his or her family request it" (Gallup, 2020). Though the Tennessee statistics on approval were not as high as the national statistic, according to the Princeton Survey Research Associates International and Vanderbilt University survey, 55% of Tennessee voters agreed that assisted-dying should be legal versus 38% who did not, a 17-point margin (Patterson, 2015). In addition, a national study of physicians showed that of the 5,200 doctors surveyed, across 29 specialties, 58% support physician-assisted death (Medscape, 2018). This aligns with the results of this study which showed that 60% of the experts supported it, while 30% did not.

Physician-assisted death was discussed during both the Tier 1 and Tier 2 interviews. As an end-of-life healthcare policy that focuses on choice, dignity at the end-of-life, and preserving patient autonomy, it was appropriate to find out what the experts and legislators thought about it. Their general opinion on the law, and their thoughts on the legislation that has been proposed in Tennessee in the past were both discussed.

Support for Legislation

There were several reasons participants gave who supported legalized physician-assisted death, the first being that it protects the physician. Legalized aid-in-dying protects doctors who prescribe from liability. It also protects the physician's autonomy. Their ability to do for their patients what is in the patient's best interest. One of the concerns of legalizing physician-assisted death is that it will create an ethical dilemma for the doctor (Park, 1998). This concern is based on the interpretation of the Hippocratic Oath and the phrase most associated with it: "first, do no harm" (Tyson, 2001). The issue is that this phrase is subjective. What is harm to one patient can be something completely different for another patient. It is between a patient and their physician to determine what harm is to them (Sonfield, 2016).

Protecting the family was another reason given for supporting legalized aid-in-dying. Similar to protecting the physician, it protects family members from civil and/or criminal prosecution. From my experience and past research, in situations where physician-assisted death is not legal, the person wanting to end their life is more likely to ask a family member for help than their doctor. This can put a family member in an awkward and dangerous situation when they are being asked to help a loved one in that manner. I have heard firsthand during interviews, for my thesis and for this research, how people were asked to help a loved one who was terminally ill and suffering (Mauck, 2016). It is hard to watch someone suffer but is even harder to watch someone you love to suffer. Participants felt that having a Death with Dignity Act in Tennessee would protect family members from impossible decisions and potential liability.

The most common reason for supporting assisted dying was that it protects patient autonomy, a person's right to decide for themselves and have self-governance over their own body and life. Of the six end-of-life healthcare experts who supported legalized physician-assisted death, all of them referred to protecting a patient's autonomy. It is the person's choice and should be something they decide with the input of their doctor and family. In Oregon, where physician-assisted death is legal, healthcare professionals agree that the main reason patients request aid-in-dying is to maintain control of themselves and remain autonomous (Ganzini, Goy, & Dobscha, 2009).

Opposition to Legislation

Feeling it is wrong to expedite death for any reason, was the main reasons participants opposed assisted dying. They explained that if end-of-life healthcare, including palliative and hospice care were used correctly, patients would have better control of their pain and other issues. This would negate the reasons some people have chosen aid-in-dying in other states. The concept of active versus passive action plays a role here. Participant who opposed assisted dying felt it was different than removing life-sustaining treatment. The idea of writing a prescription is active, turning off a ventilator even though the outcome is the same, is more passive. The rationalization is that if the ventilator had never been placed in the first place, the patient would have died naturally.

The Politics of Physician-Assisted Death

Whether a participant was for or against it, it was clear that the topic of assisted dying was very political. It was discussed that Tennessee is a conservative state. Though autonomy is celebrated in some areas of policy in the state, other areas not so much. For example, when it comes to policy on guns, the state legislature tends to promote an individual’s right to be autonomous. However, when it comes to abortion rights or assisted dying, autonomy tends to be of lesser importance. I did not specifically ask about religious influence anywhere in the interview guides, but the topic of Tennessee being in the Bible belt and a highly religious state, came up many times. Participants in both Tier 1 and Tier 2 made it clear that a lot of legislation in Tennessee is influenced by religious values.

Research shows that “most efforts to regulate morality are based on religious beliefs, and measures of religious culture provide the single best predictor of the type of morality policies a state will pursue” (Fairbanks, 1980, p. 104). This is a clear example of how end-of-life policy decisions can be complicated when religious beliefs interact with ethical decision making, and certainly impacts policy and the politics behind legalizing physician-assisted death. As the legislators discussed assisted dying, it became apparent that it is definitely a voting decision that would be driven by the moral compass, religious convictions, and gut feelings. Some of the legislators shared personal experiences that were relevant to this issue, which again confirmed that it does come down to a personal choice and that personal experience can influence a legislator’s decision. I ended my interviews with this topic, and other than the one legislator who supported it that I hadn't expected, there were really no surprises or jolting revelations revealed.

Study Limitations

Sample Size and Method

Limitations to this study include the sampling method used and the relatively small sample size. As a qualitative study, these limitations are not surprising, and in fact, somewhat expected. A purposeful sampling technique was used to recruit the participants for this study, so the sampling method was not random. Moreover, the sample size was small due to the nature of the study, the time frame it was conducted in, and the historical events that occurred during data collection. This impacted the number of participants available to be a part of the study.

Historical Events

During the course of this research, two different events impacted my ability to conduct interviews. These events occurred during the Tier 2 interviews and were beyond my control. The first event occurred on March 3, 2020 in Nashville, Tennessee. I had traveled to Nashville to conduct interviews on March 2, 2020 and March 3, 2020. Eight interviews were scheduled for the third, but a tornado destroyed East Nashville forcing the state legislature to close its offices in the Cordell Hull State Office Building. These eight interviews were rescheduled for March 17, 2020, but on the afternoon on March 16, 2020, the state legislative building was again closed to the general public due to the COVID-19 pandemic. I was only able to reschedule four of those interviews at a later date remotely.

Researcher Bias

A limitation to this study may be researcher bias. I personally coded all of the data collected for this study, and because qualitative data analysis can be a subjective process, this leaves the data open to interpretation. It is also possible that pre-conceived notions and personal motivations could have influenced the data collection and analysis. Though every attempt was made to remain objective, it is difficult to always separate personal beliefs from the data collecting and interpreting processes. However, since I conducted each of the nineteen interviews, I heard exactly what the participants said; and because of this, I have a level of understanding that goes beyond what a survey would have captured.

Contributions to Public Health

This study provides insight into an area of healthcare that is oftentimes overlooked and minimized. End-of-life healthcare in Tennessee is a growing public health issue that needs to be addressed with vigor and urgency. This exploratory dissertation uncovers areas of end-of-life healthcare that need to be improved upon, policy that could positively impact areas of weakness, and the political implications behind policy making. The knowledge gained from this research could impact the lives of millions of Tennesseans. Unlike other areas of public health, which focus on issues affecting specific populations, this research applies to every person in the state and beyond, because death avoids no one.

Conclusion

The purpose of this study was to examine the perceived quality of end-of-life healthcare in Tennessee from the perspective of the experts who work in that area of healthcare, and to discover policies that could be proposed to make necessary improvements. Specifically, I wanted to know what needed to be fixed to address end-of-life healthcare weaknesses, what the experts suggested, and how policy makers felt about the issues. The data gathered through this research and the knowledge gained, from both the experts and the legislators, will lead to a greater understanding of end-of-life healthcare in Tennessee, and what needs to be done to improve its quality. This will allow individuals faced with end-of-life decisions, and their families, to navigate the process in the best way possible.

References

(n.d.). Retrieved September 8, 2019, from http://wapp.capitol.tn.gov/apps/Billinfo/default.aspx?BillNumber=HB1040&ga=110

2019 State of Aging in Tennessee. (n.d.). Retrieved July 20, 2019, from https://www.tn.gov/aging/administration/forms-and-publications/2019-state-of-aging-in-tennessee.html

Adams, C. E., Bader, J., & Horn, K. V. (2009). Timing of Hospice Referral: Assessing Satisfaction While the Patient Receives Hospice Services. *Home Health Care Management & Practice, 21*(2), 109-116. doi:10.1177/1084822308323440

Administration on Aging. (2020). Retrieved September 3, 2020, from https://acl.gov/about-acl/administration-aging

Allison, K. C. (2010). Public health, populations, and lethal ingestion. *Disability and Health Journal, 3*(1), 56-70. doi: 10.1016/j.dhjo.2009.09.005

America's Care of Serious Illness - 2015 State-by-State Report Card on Access to Palliative Care in our Nation's Hospitals. (2015). Retrieved July 21, 2019, from https://www.capc.org/

Ames, K. (2020). How Legislators Make Decisions. Retrieved September 5, 2020, from https://www.socialstudies.org/advocacy/how-legislators-make-decisions

Baruchin, A. (2016, September 27). Having the Talk: When Treatment Becomes End-of-Life Care. Retrieved July 9, 2020, from https://www.aamc.org/news-insights/having-talk-when-treatment-becomes-end-life-care

Bass, R. (2020, January 15). Income, Poverty, Education, and Insurance in Tennessee in 2018. Retrieved September 3, 2020, from https://www.sycamoreinstitutetn.org/census-tn-economy-2018/

Batcheldor, M. (2016, April 7). Initiative seeks to encourage use of advance directives. Retrieved from https://news.vumc.org/2016/04/07/initiative-seeks-to-encourage-use-of-advance-directives/

Bernazzani, S. (2016, March). Guide to End-of-Life Care Options. Retrieved July 20, 2019, from https://www.ajmc.com/contributor/sophia-bernazzani/2016/03/guide-to-end-of-life-care-options

Bickel-Swenson, D. (2007). End-of-Life Training in U.S. Medical Schools: A Systematic Literature Review. *Journal of Palliative Medicine, 10*(1), 229-235. doi:10.1089/jpm.2006. 0102.r1

Bloom, P. B. (2013). The Public's Compass: Moral Conviction and Political Attitudes. *American Politics Research, 41*(6), 937-964. doi:10.1177/1532673x13481842

Buchbinder, M., Brassfield, E. R., & Mishra, M. (2019). Health Care Providers' Experiences with Implementing Medical Aid-in-Dying in Vermont: A Qualitative Study. *Journal of General Internal Medicine, 34*(4), 636-641. doi:10.1007/s11606-018-4811-1

Bureau, U. S. (n.d.). Census.gov. Retrieved Spring, 2019, from https://www.census.gov/

Burgess, R. G. (2016). *In the field: An introduction to field research*. Place of publication not identified: Routledge.

Behuniak S. Death with "dignity": The wedge that divides the disability rights movement from the right to die movement. *Politics and the Life Sciences*. 2011;30(01):17-32. doi:10.1017/s0730938400017652.

Béland, D., & Howlett, M. (2016). The Role and Impact of the Multiple-Streams Approach in Comparative Policy Analysis. *Journal of Comparative Policy Analysis: Research and Practice, 18*(3), 221-227. doi:10.1080/13876988.2016.1174410

Brinkmann, J. T. (2018, January). Healthcare Policy: Where It Comes from and How to Change It. Retrieved July 10, 2020, from https://opedge.com/Articles/ViewArticle/2018-01-01/healthcare-policy-where-it-comes-from-and-how-to-change-it

Brownson, R. C., Colditz, G. A., & Proctor, E. K. (2012). *Dissemination and implementation research in health: translating science to practice*. Oxford: Oxford University Press.

Campaign Launched to Increase Advance Directives in Tennessee. (2017, April 21). Retrieved July 9, 2020, from http://atomalliance.org/campaign-launched-to-increase-advance-directives-in-tennessee/

Census: Tennessee Continues to Age and Become More Diverse. (2018, June 21). Retrieved July 21, 2019, from https://news.utk.edu/2018/06/21/census-tennessee-continues-to-age-and-become-more-diverse/

Centers for Disease Control and Prevention. (2017, April 26). Retrieved November 07, 2017, from https://www.cdc.gov/

Clift, E. (2011, August 01). Hospice And The 'End Game'. Retrieved from https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2011.0197

Compassion and Choices. 2019. “Compassion & Choices.” *Compassion & Choices*. Retrieved June 1, 2019 (https://www.compassionandchoices.org/).

Corbin, J., & Morse, J. M. (2003). The Unstructured Interactive Interview: Issues of Reciprocity and Risks when Dealing with Sensitive Topics. *Qualitative Inquiry, 9*(3), 335-354. doi:10.1177/1077800403009003001

Daniels, F., III. (2015, February 15). 'Death with dignity' to be John Jay Hooker's final fight. Retrieved August 18, 2015, from http://www.tennessean.com/story/opinion/columnists/frank-daniels/2015/02/15/death-dignity-john-jay-hooker-final-fight/23378411/

Death with Dignity 2019. “Home - Death with Dignity.” *Death with Dignity*. Retrieved June 5, 2019 (http://www.deathwithdignity.org/).

Death with Dignity. 2019. “Tennessee - Death with Dignity.” *Death with Dignity*. Retrieved June 5, 2019 (https://www.deathwithdignity.org/states/tennessee/).

Dying in America: Improving quality and honoring individual preferences near the end of life. (2015). Washington, D.C.: The National Academies Press.

Emerson, Robert M., Rachel I. Fretz, and Linda L. Shaw. 2011. *Writing Ethnographic Fieldnotes*, 2nd edition. Chicago: The University of Chicago Press.

End of Life. (n.d.). Retrieved July 20, 2019, from https://www.nia.nih.gov/health/end-of-life

End-of-Life Care. (n.d.). Retrieved July 20, 2020, from https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet

Epstein, A. S., Volandes, A. E., & Oreilly, E. M. (2011). Building on Individual, State, and Federal Initiatives for Advance Care Planning, an Integral Component of Palliative and End-of-Life Cancer Care. *Journal of Oncology Practice, 7*(6), 355-359. doi:10.1200/jop.2011.000355

Ethics Report on Life and Death. (2018, December). Retrieved from https://www.medscape.com/slideshow/2018-ethics-report-life-death-6011014

Fact Sheet: Age and Socioeconomic Status. (n.d.). Retrieved July 9, 2020, from https://www.apa.org/pi/ses/resources/publications/age

Fact Sheet: Aging in the United States. (n.d.). Retrieved July 20, 2019, from https://www.prb.org/aging-unitedstates-fact-sheet/

Fairbanks, D. (1980). Politics, Economics, and the Public Morality: Why Some States are More

"Moral" Than Others. *Policy Studies Journal, 7*(4), 714-721. doi:10.1111/j.1541-0072.1979.tb01368.x

Farmer, B. (2020, January 23). Patients Want A 'Good Death' At Home, But Hospice Care Can Badly Strain Families. Retrieved July 9, 2020, from https://khn.org/news/home-hospice-care-unexpectedly-burdens-family-caregivers/

Faulkner, B. (2018, December 26). Improving Healthcare Outcomes for Senior Citizens. Retrieved July 9, 2020, from https://healthcareinamerica.us/improving-healthcare-outcomes-for-senior-citizens-85a59289

Fay, M. (2018). End-of-life Options - Hospice Costs & Who Pays for Care. Retrieved July 21, 2019, from https://www.debt.org/medical/hospice-costs/

Feinberg, L., Reinhard, S., Houser, A., & Choula, R. (2019, November 14). Valuing the Invaluable 2019 Update: Charting a Path Forward. Retrieved August 12, 2020, from https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

FINAL PALLIATIVE C Q L REPORT TASKFORCE - Tn.gov. 15 Jan. 2018, from https://www.tn.gov/content/dam/tn/aging/documents/Palliative Care Final Report 2018.pdf.

Finley, J. (2018). Caregiver Café: Providing Education and Support to Family Caregivers of Patients With Cancer. *Clinical Journal of Oncology Nursing, 22*(1), 91-96. doi:10.1188/18.cjon.91-96

Fite, E. (n.d.). Tennessee's Aging Population Faces Future with Uncertainty. *Chattanooga Times Free Press*. Retrieved July 19, 2019.

Fite, E. (2017, December 03). Workforce scrambles to keep up with aging population. Retrieved July 20, 2019, from https://www.timesfreepress.com/news/local/story/2017/dec/03/workforce-scrambles-keep-aging-population/458361/

Fletcher, H. (2015, May 20). Senior health in Tennessee ranks among worst in U.S. Retrieved July 21, 2019, from https://www.tennessean.com/story/money/industries/health-care/2015/05/20/senior-health-tennessee-among-worst-us/27602971/

Fraser, S., & Walters, J. (2000). Death - whose decision? Euthanasia and the terminally ill. *Journal of Medical Ethics, 26*(2), 121-125.

French, E., McCauley, J., Aragon, M., Bakx, P., Chalkley, M., Chen, S., Christensen, B., Chuang, H., Cote-Sergent, A., De Nardi, M., Fan, E., Echevin, D., Geoffard, P. Gestaldi-Menager, P., Gortz, M., Ibuka, Y., Jones, J., Kallestrup-Lamb, M., Karlsson, M., . . . Kelly, E. (2017). End-Of-Life Medical Spending in Last Twelve Months of Life Is Lower Than Previously Reported. *Health Affairs*, *36*(7), 1211-1217. doi:10.1377/hlthaff.2017.0174

Friesen, P. (2020). Medically Assisted Dying and Suicide: How Are They Different, and How Are They Similar? *Hastings Center Report, 50*(1), 32-43. doi:10.1002/hast.1083

Gallop Poll Social Series: Values and Beliefs (2020, May). Retrieved July 12, 2020, from https://lifenews-wpengine.netdna-ssl.com/wp-content/uploads/2020/07/gallup2020.pdf

Ganzini, L., Goy, E., Dobscha, S., & Prigerson, H. (2009). Mental Health Outcomes of Family Members of Oregonians Who Request Physician Aid in Dying. *Journal of Pain and Symptom Management, 38*(6), 807-815. doi: 10.1016/j.jpainsymman.2009.04.026

Gittell, R., Magnusson, M., & Merenda, M. (2013). *The Sustainable Business Case Book*. Flat World Knowledge.

Goffman, E. (1990). *Stigma notes on the management of spoiled identity*. New York: Penguin

Books.

Gokcekus, O., Adams, M., Grabowski, H., & Tower, E. "How Did The 2003 Prescription Drug Re-Importation Bill Pass the House?" *Economics and Politics*, vol. 18, no. 1, 2006, pp. 27–45., doi:10.1111/j.1468-0343.2006.00161. x.

Graham, J., Haidt, J., & Nosek, B. "Liberals and Conservatives Rely on Different Sets of Moral Foundations." *Journal of Personality and Social Psychology*, vol. 96, no. 5, 2009, pp. 1029–1046., doi:10.1037/a0015141.

Guillemin, M., & Gillam, L. (2004). Ethics, Reflexivity, and "Ethically Important Moments" in Research. *Qualitative Inquiry, 10*(2), 261-280. doi:10.1177/1077800403262360

Haahr, A., Norlyk, A., & Hall, E. O. (2013). Ethical challenges embedded in qualitative research interviews with close relatives. *Nursing Ethics, 21*(1), 6-15. doi:10.1177/0969733013486370

Haider-Markel, D., & Meier, K. "The Politics of Gay and Lesbian Rights: Expanding the Scope of the Conflict." *The Journal of Politics*, vol. 58, no. 2, 1996, pp. 332–349., doi:10.2307/2960229.

Hallman, B. (2014, June 19). How Dying Became a Multibillion-Dollar Industry. Retrieved July 20, 2019, from http://projects.huffingtonpost.com/hospice-inc

Health Care Decision Making. (2019). Retrieved July 20, 2019, from https://www.tn.gov/health/health-program-areas/health-professional-boards/hcf-board/hcf-board/advance-directives.html

Health Care Facilities. (n.d.). Retrieved June 5, 2019, from https://apps.health.tn.gov/facilityListings/

Healy, M. (2013, May 29). Senior health care crisis looms; report ranks states. Retrieved July 19, 2019, from https://www.usatoday.com/story/news/nation/2013/05/28/senior-citizens-health-care-report/2354635/

Hess, K., LGSW. (2020, October 01). America's Death-Denying Culture - Brighton Hospice Minnesota. Retrieved November 2, 2020, from https://brightonhospice.com/death-denying-culture/

Hewitt, J. (2007). Ethical Components of Researcher—Researched Relationships in Qualitative Interviewing. *Qualitative Health Research*, *17*(8), 1149-1159. doi:10.1177/1049732307308305

Hoffman, D., & Zucker, H. (2016). A Call to Preventive Action by Health Care Providers and Policy Makers to Support Caregivers. *Preventing Chronic Disease, 13*. doi:10.5888/pcd13.160233

Hogan, C., Lunney, J., Gabel, J., & Lynn, J. (2001). Medicare Beneficiaries' Costs of Care in The Last Year of Life. *Health Affairs, 20*(4), 188-195. doi:10.1377/hlthaff.20.4.188

Holly, R. (2018, July 23). House Passes Bipartisan Hospice Bill Strengthening ... Retrieved July 19, 2019, from https://homehealthcarenews.com/2018/07/house-passes-bipartisan-hospice-bill-strengthening-physician-training-patient-outreach/

Holly, R., & Holly, R. (2019, January 07). These States Are Most Concerned About End-of-Life Issues. Retrieved July 20, 2019, from https://homehealthcarenews.com/2019/01/these-states-are-most-concerned-about-end-of-life-issues/

Horowitz, R., Gramling, R., & Quill, T. (2014). Palliative care education in US medical schools. *Medical Education, 48*(1), 59-66. doi:10.1111/medu.12292

Hospice Care Overview for Professionals. (2019, October 21). Retrieved September 3, 2020, from https://www.nhpco.org/hospice-care-overview/

Hospice Facts & Figures. (2019, July 2). Retrieved July 19, 2019, from https://www.nhpco.org/research

Hostetter, M., & Klein, S. (n.d.). Improving Care at the End of Life. Retrieved July 9, 2020, from https://www.commonwealthfund.org/publications/newsletter-article/improving-care-end-life

House of Representatives. (n.d.). Retrieved June 5, 2019, from http://www.capitol.tn.gov/house/members/

Hui, D., Mori, M., Parsons, H. A., Kim, S. H., Li, Z., Damani, S., & Bruera, E. (2012). The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature. *Journal of Pain and Symptom Management*, *43*(3), 582-592. doi:10.1016/j.jpainsymman.2011.04.016

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., Cruz, M., Kim, S., Kwon, J., Hutchins, R., Liem, C., Bruera, E. (2014). Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review. *Journal of Pain and Symptom Management, 47*(1), 77-89. doi:10.1016/j.jpainsymman.2013.02.021

Hurka, S., Adam, C., Knill, C. “Is Morality Policy Different? Testing Sectoral and Institutional Explanations of Policy Change.” *Policy Studies Journal*, vol. 45, no. 4, 2016, pp. 688–712., doi:10.1111/psj.12153.

Jacobs, L., Burns, K., & Jacobs, B. (2008). Trauma Death: Views of the public and trauma professionals on death and dying from injuries. *Archives of Surgery, 143*(8), 730. doi:10.1001/archsurg.143.8.730

Jaffe, I. (2017, August 11). Nearly 1 In 5 Hospice Patients Discharged While Still Alive.

Retrieved July 20, 2019, from https://www.npr.org/sections/health-shots/2017/08/11/542607941/nearly-1-in-5-hospice-patients-discharged-while-still-alive

Japsen, B. (2019, June 07). A Shortage of End-Of-Life Doctors Is Coming. Retrieved July 9, 2020, from https://www.forbes.com/sites/brucejapsen/2019/06/03/a-major-shortage-of-end-of-life-doctors-is-coming/

Jha, A. (2018). End-of-Life Care, Not End-of-Life Spending. *Jama, 320*(7), 631. doi:10.1001/jama.2018.11177

Johnson, D. (2018, August 02). Enhanced Physician Training and Support Are Needed to Improve End-Of-Life Care. Retrieved July 9, 2020, from https://www.healthaffairs.org/do/10.1377/hblog20180730.54577/full/

Kamal, A., Wolf, S., Troy, J., Leff, V., Dahlin, C., Rotella, J., Handzo, G., Rodgers, P., & Myers, E. (2019). Policy Changes Key to Promoting Sustainability and Growth of The Specialty Palliative Care Workforce. *Health Affairs, 38*(6), 910-918. doi:10.1377/hlthaff.2019.00018

Karnik, S., & Kanekar, A. (2016). Ethical Issues Surrounding End-of-Life Care: A Narrative Review. *Healthcare, 4*(2), 24. doi:10.3390/healthcare4020024

Kingdon, J. (2014). *Agendas, alternatives, and public policies*. Harlow: Pearson Education Limited.

Kelley, A., McGarry, K., Gorges, R., & Skinner, J. (2015). The Burden of Health Care Costs for Patients with Dementia in the Last 5 Years of Life. *Annals of Internal Medicine, 163*(10), 729. doi:10.7326/m15-0381

Kleinman, S., & Copp, M. (2010). *Emotions and fieldwork*. Newbury Park: Sage Publications.

Kluss, T. (n.d.). Reframing Aging Initiative Beta. Retrieved July 10, 2020, from https://www.geron.org/programs-services/reframing-aging-initiative

Kreitzer, R. “Politics and Morality in State Abortion Policy.” *State Politics & Policy Quarterly*, vol. 15, no. 1, 2015, pp. 41–66., doi:10.1177/1532440014561868.

Kumar, P., Wright, A., Hatfield, L., Temel, J., & Keating, N. (2017). Family Perspectives on Hospice Care Experiences of Patients with Cancer. *Journal of Clinical Oncology, 35*(4), 432-439. doi:10.1200/jco.2016.68.9257

Lee, B. (2003). *Compassion in Dying: stories of dignity and choice*. Troutdale, Or. New Sage Press.

Lee, B. 2014. “Oregon's Experience with Aid in Dying: Findings from the Death with Dignity Laboratory.” *Annals of the New York Academy of Sciences* 1330(1):94–100.

LinkedIn. (n.d.). Retrieved from https://www.linkedin.com/feed/?trk=guest_homepage-basic_nav-header-signin

Lofland, J. (1971). *Analyzing social settings; a guide to qualitative observation and analysis*. Belmont, CA: Wadsworth Pub.

Long-Term Services & Supports State Scorecard. (2017). Retrieved Fall, 2017, from http://www.longtermscorecard.org/

Lowey, S. (2015). *Nursing care at the end of life: What every clinician should know*. Geneseo, NY: Open SUNY Textbooks.

Lyu, H., Xu, T., Brotman, D., Mayer-Blackwell, B., Cooper, M., Daniel, M., Wick, E., Saini, V., Brownlee, S., & Makary, M. (2017). Overtreatment in the United States. *Plos One, 12*(9). doi:10.1371/journal.pone.0181970

Mauck, E. (2016). Oregon's Death with Dignity Act: Socially Constructing a Good Death. Retrieved from https://dc.etsu.edu/etd/3043/

McCrae R. Social consequences of experiential openness. *Psychological Bulletin*. 1996;120(3):323-337. doi:10.1037//0033-2909.120.3.323.

Meghani, S., & Hinds, P. (2014, December 11). Policy brief: The Institute of Medicine report Dying in America: Improving quality and honoring individual preferences near the end of life. Retrieved October 11, 2017, from https://www.sciencedirect.com/science/article/pii/S0029655414002565

Mooney, C. "The Politics of Morality Policy: Symposium Editors Introduction." *Policy Studies Journal*, vol. 27, no. 4, 1999, pp. 675–680., doi:10.1111/j.1541-0072.1999.tb01995.x.

Mooney, C., & Schuldt, R. "Does Morality Policy Exist? Testing a Basic Assumption." *Policy Studies Journal*, vol. 36, no. 2, 2008, pp. 199–218., doi:10.1111/j.1541-0072.2008.00262.x.

Mor, V. (2017, July 10). End-Of-Life Policy Solutions: A Cautionary Note. Retrieved July 10, 2020, from https://www.healthaffairs.org/do/10.1377/hblog20170710.060992/full/

Morhaim, D., & Pollack, K. (2013). End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis. *American Journal of Public Health, 103*(6). doi:10.2105/ajph.2013.301316

Mucciaroni, G. "Are Debates about 'Morality Policy' Really about Morality? Framing Opposition to Gay and Lesbian Rights." *Policy Studies Journal*, vol. 39, no. 2, 2011, pp. 187–216., doi:10.1111/j.1541-0072.2011.00404.x.

National Family Caregiver Support Program. (n.d.). Retrieved July 10, 2020, from https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program

National Hospice and Palliative Care Organization. (n.d.). Retrieved September 18, 2017, from https://www.nhpco.org/

New Advance Directives Campaign Urges People to Have “The ... (n.d.). Retrieved July 10, 2020, from https://www.lpk.com/latest/2018/10/30/advance-directives-campaign/

Norman, J. (2013, March 4). The Aging Population: A Crisis in Plain Sight. Retrieved July 21, 2019, from https://www.commonwealthfund.org/publications/newsletter-article/aging-population-crisis-plain-sight

O'Donovan, K., Sarbaugh-Thompson, M., & Betz, S. (2016). What Makes a Decision Difficult for State Legislators? Retrieved August 5, 2020, from https://www.utdallas.edu/sppc/pdf/O'Donovan%20Sarbaugh-Thompson%20and%20Betz.pdf

Omori, M. “Moral Panics and Morality Policy.” *Journal of Drug Issues*, vol. 43, no. 4, 2013, pp. 517–534., doi:10.1177/0022042613491101.

Oregon Department of Public Health. 2019. “Death with Dignity Act.” *Death with Dignity Act*. Retrieved June 6, 2019 (http://public.health.oregon.gov/providerpartnerresources /evaluationresearch /deathwithdignityact/pages/index.aspx).

Orfali, R. (2011). *Death with dignity: the case for legalizing physician-assisted dying and Euthanasia*. Minneapolis, MN: Mill City Press.

Park, E. (1998). “Physician-Assisted Suicide: State Legislation Teetering at the Pinnacle of a Slippery Slope.” *William &Mary Bill of Rights Journal* 7(1), 1998 pp. 227–304.

Patients' Rights to Self-Determination at the End of Life. (2008, October 8). Retrieved September 23, 2017, from https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life

Patterson, J. (1970, May 13). The full General Assembly should vote on Insure Tennessee:

Vanderbilt Poll. Retrieved August 12, 2020, from https://news.vanderbilt.edu/2015/05/13/the-full-general-assembly-should-vote-on-insure-tennessee-vanderbilt-poll/

Paturel, A. (2019, January 14). Let's talk about death. Retrieved July 9, 2020, from https://www.aamc.org/news-insights/let-s-talk-about-death

Phelps, A., Maciejewski, P., Nilsson, M., Balboni, T., Wright, A., Paulk, M., Trice, E., Schrag, D., Peteet, J., Block, S., & Prigerson, H. (2009). Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients with Advanced Cancer. *Jama, 301*(11), 1140. doi:10.1001/jama.2009.341

Pizzo, P. (2016). Thoughts about Dying in America: Enhancing the impact of one's life journey and legacy by also planning for the end of life: Table 1. *Proceedings of the National Academy of Sciences, 113*(46), 12908-12912. doi:10.1073/pnas.1614266113

Preparing and Planning for Life's Final Chapter. (2015). Retrieved July 20, 2019, from https://www.coamidtn.org/

Qualitative, Quantitative and Mixed Methods. (n.d.). Retrieved June 8, 2019, from http://dissertation.laerd.com/getting-started-p2.php

QSR International Pty Ltd. (2020). NVivo qualitative data analysis software.

Quill, T. (2004). Dying and Decision Making. *New England Journal of Medicine, 351*(6), 611-612. Doi: 10.1056/nejm200408053510620

Quill, T. (2008). Physician-Assisted Death in the United States: Are the Existing "Last Resorts" Enough? *Hastings Center Report, 38*(5), 17-22. doi:10.1353/hcr.0.0051

Rao, J. (2015). Engaging Public Health in End-of-Life Issues: It Is Time to Step Up to the Plate. *Annals of Internal Medicine, 162*(3), 230. Doi: 10.7326/m14-2479

Reframing Aging. (n.d.). Retrieved July 10, 2020, from https://www.asaging.org/web-seminars/reframing-aging-healthcare-sector

Reinhard, S., Feinberg, L., Houser, A., Choula, R., & Evans, M. (2019). Valuing the Invaluable: 2019 Update: Charting a Path Forward. doi:10.26419/ppi.00082.001

Roff, S. "Analyzing End-of-Life Care Legislation." *Social Work in Health Care*, vol. 33, no. 1, 2001, pp. 51–68., doi:10.1300/j010v33n01_05.

Rubin, H., & Rubin, I. (1995). *Qualitative Interviewing: The art of hearing data*. Thousand Oaks: Sage.

Schockett, E., Teno, J., Miller, S., & Stuart, B. (2005). Late Referral to Hospice and Bereaved Family Member Perception of Quality of End-of-Life Care. *Journal of Pain and Symptom Management, 30*(5), 400-407. doi:10.1016/j.jpainsymman.2005.04.013

Schreiber, S., & Wyatt, K. (2019, July 10). Why it Matters. Retrieved July 9, 2020, from http://www.ohioshospice.org/whyitmatters/

Silveira, M., Kim, S., & Langa, K. (2010). Advance Directives and Outcomes of Surrogate Decision Making before Death. *New England Journal of Medicine, 362*(13), 1211-1218. doi:10.1056/nejmsa0907901

Silvestri, G., Knittig, S., Zoller, J., & Nietert, P. (2003). Importance of Faith on Medical Decisions Regarding Cancer Care. *Journal of Clinical Oncology, 21*(7), 1379-1382. doi:10.1200/jco.2003.08.036

Smith, R. (2000). A good death. *BMJ, 320*(Suppl S3), 00032. doi:10.1136/sbmj.00032

Sonfield, A., & Guttmacher Institute. (2016, December 06). Rights vs. Responsibilities: Professional Standards and Provider Refusals. Retrieved from https://www.guttmacher.org/gpr/2005/08/rights-vs-responsibilities-professional-standards-and-provider-refusals

Spencer, K., Mrig, E., Matlock, D., & Kessler, E. (2017). A Qualitative Investigation of Cross-domain Influences on Medical Decision Making and the Importance of Social Context for Understanding Barriers to Hospice Use. *Journal of Applied Social Science, 11*(1), 48-59. doi:10.1177/1936724417692377

Staff, T. (2014, September 15). Defining Public Health Emergencies. Retrieved July 21, 2019, from http://blog.petrieflom.law.harvard.edu/2014/09/15/defining-public-health-emergencies/

Sulmasy, L., & Mueller, P. "Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper." *Annals of Internal Medicine*, vol. 167, no. 8, 2017, p. 576., doi:10.7326/m17-0938.

Taft, S., & Nanna, K. (2008). What Are the Sources of Health Policy That Influence Nursing Practice? *Policy, Politics, & Nursing Practice, 9*(4), 274-287. doi:10.1177/1527154408319287

Tatalovich, R., & Daynes, B. *Moral Controversies in American Politics: 4th*. M.e. Sharpe, 2011.

Tennessee Culture - Tennessee History - Grand Divisions - THS. (2017, October 04). Retrieved from https://www.tennesseehistory.org/grand-divisions/

Tennessee State Government. (n.d.). Retrieved January 6, 2019, from http://www.tn.gov/

Tobarran, N., & Byrne, T. (2016). Accelerated Medical Education: Impact of a 48 Hour Hospice Home Immersion. *Journal of Gerontology & Geriatric Research, 5*(3). doi:10.4172/2167-7182.1000299

Tolbert, A. (2016, May 06). End-of-life care services growing in Nashville. Retrieved July 20, 2019, from https://www.tennessean.com/story/money/industries/healthcare/2016/05/06/end--life-care-services-growing-nashville/83942898/

Tolle, S., & Teno, J. (2017). Lessons from Oregon in Embracing Complexity in End-of-Life Care. *New England Journal of Medicine, 376*(11), 1078-1082. Doi: 10.1056/nejmsb1612511

Tolley, E. (2016). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey-Bass & Pfeiffer Imprints, Wiley.

True, G., Phipps, E., Braitman, L., Harralson, T., Harris, D., & Tester, W. (2005). Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Annals of Behavioral Medicine, 30*(2), 174-179. doi:10.1207/s15324796abm3002_10

Tuggey, E., & Lewin, W. (2014). A multidisciplinary approach in providing transitional care for patients with advanced cancer. *Annals of Palliative Medicine*, *3*(3), 139-143.

Tyson, P. (2001, March 27). The Hippocratic Oath Today. Retrieved from https://www.pbs.org/wgbh/nova/article/hippocratic-oath-today/

US Census Bureau. (2018). American Community Survey 1-Year Estimates for 2013-2018. Retrieved September 5, 2020, from https://www.census.gov/acs/www/data/data-tables-and-tools/data-profiles/2018/

US Census Bureau. (2018, December 03). Older People Projected to Outnumber Children. Retrieved July 20, 2019, from https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html

VanderStoep, S., & Johnston, D. (2009). *Research methods for everyday life: Blending qualitative and quantitative approaches*. San Francisco: Jossey-Bass.

Wasserman, L. (2008). Respectful Death: A Model for End-of-Life Care. *Clinical Journal of*

Oncology Nursing, 12(4), 621-626. doi: 10.1188/08.cjon.621-626

What Do We Mean by Health and Aging Policy? (2018). Retrieved July 20, 2019, from https://www.healthandagingpolicy.org/

What end of life care involves. (n.d.). Retrieved July 9, 2020, from https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/

What is TELP? (2019). Retrieved July 21, 2019, from https://endoflifecaretn.org/what-is-telp/

Yadav, K., Gabler, N., Cooney, E., Kent, S., Kim, J., Herbst, N., Mante, A., Halpern, S., & Courtright, K. (2017). Approximately One in Three US Adults Completes Any Type of Advance Directive for End-Of-Life Care. *Health Affairs, 36*(7), 1244-1251. doi:10.1377/hlthaff.2017.0175

Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine, 18*(2), 121-128. doi:10.1191/0269216304pm858oa

Zimmermann, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., Tannock, I., & Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal, 188*(10). doi:10.1503/cmaj.151171

APPENDICES

Appendix A: Participant Contact Script – Tier 1

PARTICIPANT CONTACT SCRIPT

Title: A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions

Principal Investigator: Erin Mauck

EMAIL SCRIPT:

Dear (Name Here):

I would like to hear your thoughts about end-of-life healthcare in Tennessee. My name is Erin Mauck and I am a doctoral candidate in the College of Public Health at East Tennessee State University. My main area of interest is end-of-life healthcare and I am currently doing research for my dissertation which is titled "A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions".

Over the last three months I have interviewed ten of the state's leading experts in areas of end-of-life healthcare. I am now planning to interview members of both the House and Senate health committees and would value the opportunity to speak with you for a 15 to 20-minutes. I am especially interested in your views regarding end-of-life healthcare in Tennessee, decision making, and healthcare policy. This interview will be conducted with complete confidentiality, with nothing discussed being directly attributed to you in my findings.

If you are willing to assist me in my research, we can set up an interview by phone or in person, whichever works best for you. My schedule is very flexible, so I can work with your schedule. I look forward to hearing from you.

Sincerely,

Erin E. Mauck

Appendix B: Participant Contact Script – Tier 2

PARTICIPANT CONTACT SCRIPT

Title: A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions

Principal Investigator: Erin Mauck

EMAIL SCRIPT:

Dear (Name Here):

I would like to hear your thoughts about end-of-life healthcare in Tennessee. My name is Erin Mauck and I am a doctoral candidate in the College of Public Health at East Tennessee State University. My main area of interest is end-of-life healthcare and I am currently doing research for my dissertation which is titled "A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions".

Over the last three months I have interviewed ten of the state's leading experts in areas of end-of-life healthcare. I am now planning to interview members of both the House and Senate health committees and would value the opportunity to speak with you for a 15 to 20-minutes. I am especially interested in your views regarding end-of-life healthcare in Tennessee, decision making, and healthcare policy. This interview will be conducted with complete confidentiality, with nothing discussed being directly attributed to you in my findings.

If you are willing to assist me in my research, we can set up an interview by phone or in person, whichever works best for you. My schedule is very flexible, so I can work with your schedule. I look forward to hearing from you.

Sincerely,

Erin E. Mauck

Appendix C: Interview Guide – Tier 1

Interview Guide (Tier 1)

Interview Pseudonym ______________________________________

Location _________________________ Date ___________________

1) Will you share with me a little bit about *how* you came to be a(n) ________________? (Background)

2) In your position as a(n) _________________, will you share with me a little about what you do? (Clarifying)

3) Over the last few years, the discussion around the aging population has grown. Both nationally, and in Tennessee. What are your thoughts on that? (Problem Stream)

4) According to an article in the Chattanooga Times Free Press, Tennessee's aging population faces an uncertain future because State programs have limited capacity and minimal funds to meet the demands of the aging population. What are your thoughts on that subject? (Problem Stream)

5) When I say "end-of-life" healthcare, what do you think of? (Clarifying)

6) From your perspective, what are the strengths of end-of-life healthcare in Tennessee? (Clarifying)

7) What are the weaknesses? (Problem Stream)

8) Tennessee currently has 6 residential hospice facilities with 108 beds in the state, down from 8 residential hospice facilities with 148 beds two years ago. What are your thoughts as to adequacy of care? (Problem Stream)

9) In several national reports, Tennessee ranks in the bottom 20% in various areas of end-of-life healthcare, including palliative care and long-term services and support. Would you talk with me a little about that? (Problem Stream)

10) Nationally, fewer than 10% of medical schools offer education on the process of death and dying to their students. Why do you think that is? (Problem Stream)

11) In your professional opinion, what could the state of Tennessee do to increase the use of Advance Directives? (Policy Stream)

12) End-of-life healthcare policy can sometimes include controversial topics in medicine including removal of feeding tubes, refusal of treatments, discontinuing life support, and assisted dying. In fact, physician-assisted death has been legalized in 7 states, and Washington D.C. Will you share your thoughts about that? (Politics Stream)

13) Physician-assisted death legislation has been proposed in Tennessee three times since 2015 (once in 2015 and twice in 2017). Both republican and democratic legislators have proposed this legislation? What are your thoughts on that? (Policy Stream)

14) What are your thoughts about assisted dying? (Politics Stream)

15) In your opinion, what are some of the most important things the state of Tennessee needs to do to improve the overall quality of end-of-life healthcare? (Policy Stream)

16) Is there anything else you would like to add? (Clarifying)

CONCLUDE

Appendix D: Interview Guide – Tier 2

Interview Guide (Tier 2 - Legislators)

Interview Pseudonym ______________________________________

Location _________________________ Date ___________________

1) What areas of policy are you most passionate about? (Policy Stream)

2) Will you talk to me about what guides or shapes your decisions when you vote on policy? (Or… How do you make up your mind?) (If needed to prompt: Personal? Moral? Religious? Personal experiences?) (Policy Stream)

3) When I say “end-of-life” healthcare, what do you think of? (Clarifying)

4) When I say “end-of-life” healthcare *policy*, what do you think of? (Clarifying)

5) Can you tell me about a time when you were conflicted about a vote? About whether you would vote for or against an issue? (Politics Stream)

6) During my interviews with end-of-life healthcare experts in Tennessee, there was a discussion about Advance Directives. One of the suggestions was for the legislation to promote a statewide initiative to promote them. What are your thoughts about that? (Policy Stream)

7) A concern that was brought to my attention during my interviews with the experts, was the lack of family caregiver support in the area of end-of-life healthcare. In your opinion, what could the legislation do to address this? (Policy Stream)

8) End-of-life healthcare policy can sometimes include controversial topics including removal of feeding tubes, refusal of treatments, discontinuing life support, and assisted dying. Will you share your thoughts about that? (Politics Stream)

9) Is there anything else you would like to add? (Clarifying)

CONCLUDE

Appendix E: Participant Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Title: A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions

Principal Investigator: Erin Mauck

This Informed Consent Document explains your participation in a research project conducted by Erin Mauck, a doctoral candidate at East Tennessee State University (ETSU). It is important that you read this material carefully and then decide if you wish to participate.

PURPOSE OF RESEARCH:

This research will examine the motivation behind participation in organizations involved with areas of end-of-life healthcare in Tennessee and will critically assess the processes that Tennessee state legislators, State department directors, and other stakeholders employ specifically when it applies to end-of-life healthcare policy. It will also measure the support for end-of-life healthcare policy that would improve quality of care and expand options for terminally ill Tennesseans while critically assessing the policy-making process that Tennessee state legislators employ. Specifically, when it applies to end-of-life healthcare policy.

YOUR RIGHTS:

It is important for you to know that:

Your participation is entirely voluntary.

You may decide not to take part or decide to quit the study at any time.

You may contact your personal physician if any of the questions upset you.

You will be told about any new information or changes in the study that might affect your willingness to participate.

PROCEDURES:

Participating in this project involves a personal interview. Consider this interview to be a conversation with questions you may answer if you choose. You may stop the interview at any time and skip any question you do not want to answer. With your permission, the interview will be audio recorded to ensure that I accurately note your responses. If you do not wish to be audio recorded, we can still proceed with the interview and I will take written notes.

DURATION:

The interview is expected to last 45-60 minutes.

RISKS:

There are minimal risks to study participants. The possible risks associated with this study include feelings of discomfort while discussing the importance of end-of-life healthcare in Tennessee, and because each interview will be audio-recorded, there is a potential risk of loss of confidentiality. You may choose to withdraw from the study at any time. I will do my best to maintain confidentiality by ensuring that we do not keep any individually identifiable information. The audio recordings will be destroyed once the interview has been transcribed and participant names will be converted to a pseudonym in the transcription process. Any information provided will not be attributed to you.

BENEFITS:

There will be no compensation, monetary or otherwise, or direct benefits for participation in this project. However, it is anticipated that the knowledge gained from this research will lead to the enactment of end-of-life healthcare policy in Tennessee. The state will see improvements in all aspects of end-of-life healthcare, specifically in the areas of affordability, access to hospice and palliative care, choice of setting, choice of provider, quality of life, quality of care, and support for family caregivers. Other improvements could include increased communication between patient and provider, mandatory professional development and education in end-of-life healthcare decision making for medical professionals, increased use of advance directives, and eventually expanded choices in end-of-life healthcare.

VOLUNTARY PARTICIPATION:

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You may refuse to participate. You may quit at any time. You may quit by calling Erin Mauck at (423)328-6217.

CONFIDENTIALITY:

Your privacy is important. Every attempt will be made to keep your study results confidential. The results of this study may be published and/or presented at meetings without naming you as a subject. In research records, you will be identified by a pseudonym. Although your rights and privacy will be maintained, the Principal Investigator, and the ETSU IRB will have access to the study records. Your information or will not be used for any future studies.

QUESTIONS:

Before you sign this consent form, please feel free to ask any questions you may have about the study or about your rights as a research subject. If you have questions, concerns, or complaints, or think the research has hurt you, you may talk to Erin Mauck at (423)328-6217, the Principal Investigator or Dr. Deborah Slawson at (423)439-4592. You may also call the Director of the Institutional Review Board at (423)439-6054. If you have any questions or concerns about the research and want to talk to someone independent of the research team, you may call an IRB Coordinator at (423)439-6055. You may take as much time as needed to think this over.

CONSENT TO PARTICIPATE IN THE RESEARCH PROJECT

Title: A Qualitative Analysis of End-of-Life Healthcare in Tennessee: Politics, Principles, and Perceptions

I understand the purpose and procedures of this research project and the predictable discomfort, risks, and benefits that might result. I have had an opportunity to discuss the risks and benefits of this research with the investigator and all of my questions have been answered. By signing below, I confirm that I am at least 18 years of age. I agree to participate as a volunteer in this research project and be audio recorded. I understand that I may end my participation at any time. I have been given a copy of this consent form.

____

Signature of Participant Date

____

Printed Name of Participant

____

Signature of Principal Investigator Date

Appendix F: Tier 1 Codebook

Impact Area	**Interview Questions**	**Node**	**Child Node**	**Sub-Node**	**Description**
Background and Motivation	1) Will you share with me a little bit about how you came to be a(n)__________? PROBE: What led you to do the work that you do now?	**Background**			**What motivated the expert to choose a field in end-of-life healthcare.**
			Personal Experience		Participants share an experience that shaped their career choice. Ex: death of someone
				Positive	
				Negative	
			Personal Interest		
			Job Opportunity		
				New field	
				Promotion	
			Recommendation		
				Impactful mentor	
			Passion for it		
				Wanted to make a difference	
				It was a "calling"	
			Other		
Validation of Expert Status	2) In your position as a(n) __________, will you share with me a little about what you do?	**Role of Expert**			**What they do on a daily or weekly basis in their profession**
			Hospice Care		Care designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible
				Nurse	

				Doctor	
				Director	
			Geriatrics		A branch of medicine that deals with the problems and diseases of old age and the medical care and treatment of aging
				Nurse	
				Doctor	
			University employee		
				Dean	
				Professor	
			Entrepreneur		A person who organizes and operates a business or businesses, taking on greater than normal financial risks in order to do so
			State of Tennessee		
				Director	
				Employee	
			Palliative Care		Specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family
				Nurse	
				Doctor	
				Director	
			Inpatient work		
			Outpatient work		
			Team-based approach		The provision of health services to individuals, families, and/or their communities by two or more healthcare providers who work collaboratively with patients and their caregivers
Problem Stream	3) Over the last few years, the discussion around the aging population has grown. Both nationally, and in Tennessee. What are your thoughts on that?	**Aging Population**			**How is the aging population impacting their specific field and what they think about it**

			Gaps		Areas of healthcare where there are weaknesses or deficiencies
				Not enough of any healthcare	
				Not enough skilled nursing facilities	
				Not enough funding	
				No family support	
				Not enough providers	
				Lack of caregivers	
			Discussion of 2030		By the year 2030 there will be a significant increase in population over 65
			Increased need		
			Rural versus urban		Seeing more of an increase in rural areas than urban
				People are living longer in some areas	
				Younger people moving to urban areas	
			Will be a temporary issue		It is not a problem that will be permanent. It will be a temporary situation
				Will peak and then drop off again	
			We are prepared for it		
				Hospitals have capacity	
			Need more providers		Providers that are educated and prepared to assist the elderly population
				Geriatric training needed	Includes doctors, nurse practitioners, and physician assistants
				Primary care providers needed	
			Need to reframe aging		Designed to improve the public's understanding of what aging means and the many ways that older people contribute to our society
				Provide education	To healthcare workers, legislators, and/or the general public
				Develop programs	

			Other		
Problem Stream	4) According to an article in the Chattanooga Times Free Press, Tennessee's aging population faces an uncertain future because State programs have limited capacity and minimal funds to meet the demands of the aging population. What are your thoughts on that subject?	**State Programs for the Aging Population**			**What their opinion is on the state's ability to address the aging population**
			Medicare		
				Show them what we need	
				Does not cover long-term services	Long-term care is a variety of services which help meet both the medical and non-medical needs of people with a chronic illness or disability who cannot care for themselves for long periods
				Need a Medicare increase	
				Does not cover vision, hearing, dental	Things that people need more when they get older
				Fee for service is a disservice	Fee-for-service is a payment model where services are unbundled and paid for separately. In health care, it gives an incentive for physicians to provide more treatments because payment is dependent on the quantity of care, rather than quality of care
			Research		
				Use data to get more funds	
			Lack of money - Personal		
				Individuals do not have savings	

				People overspend on other things	
				Long-term care is very expensive	Long-term care is a variety of services which help meet both the medical and non-medical needs of people with a chronic illness or disability who cannot care for themselves for long periods
			Lack of money - Government		
				Lack of funding	
				Medicare and Ten care	They come under the department of finance
			Tennessee's current status		
				Not providing good care	
				Lowest ranking of all states	
				Have waiting lists for assistance	Refers to the Community Options program for the elderly in Tennessee
				We rank below progressive states	
				Worse for people who are poor	
			Culture		
				Proud people	Tennesseans are proud and independent and do not want to use Medicaid services
				Death avoidant	Death is a topic that most people avoid discussing or preparing for
				Lack of trust	May not trust documents needed so they do not prepare
			Preparation		
				Need to plan for end-of-life	
				Need to have an advance directive	An advance directive is a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor
				Need to have a will	
			Other		

Clarification	5) When I say "end-of-life" healthcare, what do you think of?	**End-of-Life Healthcare Defined**			**How does the expert define "end-of-life healthcare"**
			Palliative Care		Specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family
			Hospice Care		Care designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible
			Lifelong healthcare		Healthcare that starts the day you are born and continues throughout life
			Location of care		Where end-of-life healthcare is given. A physical location
				Hospital	
				Nursing home	
				At home	
				Long-term care facility	
				Residential hospice	
			Things missed		
				Missed opportunities	
				Missed experiences	
			Misunderstandings		
				Between doctors and patients	
				Between doctors and families	
				Between palliative and hospice care	
				About what palliative care is	
			Planning for future care		

				Talk about Goals of Care	Goals of care are the aims for a person's care, as agreed between him/her, his/her family, careers, and healthcare team. A person's goals of care are not always restricted to medical care. Goals of care in end-of-life healthcare will change over time, particularly as the person enters the terminal phase
				Long-term view of end-of-life care	
				Comfort Measures	Refers to medical treatment of a dying person where the natural dying process is permitted to occur while assuring maximum comfort. It includes attention to the psychological and spiritual needs of the patient and support for both the dying patient and the patient's family
				Quality of life	Quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably to a lesser extent to meaning and fulfillment
			Terminal Diagnosis		A disease or condition which can't be cured and is likely to lead to someone's death
				Life ending	A diagnosis that denotes impending death
				Life limiting	Life-limiting illness is a term used to describe an incurable condition that will shorten a person's life, though they may continue to live active lives for many years
			Time frame		
				Specific time frame	
				No time frame	
			Other		
Clarification	6) From your perspective, what are the strengths of end-of-life healthcare in Tennessee?	**End-of-Life Healthcare Strengths**			**What the expert thinks are the strengths or positive areas of end-of-life healthcare in the state**
			Their own employer		Participants described their own place of employment
			It is expanding		Certain aspects of end-of-life healthcare are growing in different parts of Tennessee

			Medical community		Refers to doctors, nurses, and other end-of-life healthcare workers
				Knowledgeable	
				Caring	
			There is a renewed interest		More healthcare workers are becoming interested in end-of-life issues
			Some good hospice agencies		Based on location and hospice entity
			Based on location		
				Urban	
				Rural	
			Medical advances		
				Systematic	Advances made in the area of large systems, such as hospitals and government
				Programmatic	Advances made in the area of specific areas of healthcare, such as hospice or palliative
				Clinical	Advances made in the area of diagnosis, treatment, and care
Problem Stream	7) What are the weaknesses?	**End-of-Life Healthcare Weaknesses**			**What the expert thinks are the weaknesses or negative areas of end-of-life healthcare in the state**
			Gaps		Areas of healthcare where there are weaknesses or deficiencies
				Primary care	
				Outpatient base	
				Population health	
				Lack of education	Healthcare workers are not educated in areas of end-of-life healthcare or death and dying
			Staffing		
				Staff turnover	
				Their heart is not in it	
				End-of-life healthcare is hard work	
				Emotionally difficult	
			Stigma around hospice		
			Access to care		People are unable to access good end-of-life healthcare

			Patients referred too late		Patients are being referred to hospice much later than they should be
			Doctors can't have difficult conversations		
				Were not trained to have them	
				Unsure of prognosis	
				Don’t have the time	
			Ulterior motives		An alternative or extrinsic reason for doing something, especially when concealed or when differing from the stated or apparent reason.
				Financial gain in some fields	
				Do not want to lose patient revenue	
			Lack of caregiver support		
			Lack of patient financial resources		
			Treatment options		
				Lack of	
				Overly administered	
			Other		
Problem Stream	8) Tennessee currently has 6 residential hospice facilities with 108 beds in the state, down from 8 residential hospice facilities with 148 beds two years ago. What are your thoughts as to adequacy of care?	**Current Hospice Status in Tennessee**			**What the expert's thoughts on the limited number of residential hospice facilities in the state are. Does it impact the adequacy of care?**
			Other options		There is not always a need for residential hospice because there are other options
				Nursing homes	
				Hospitals	
				Hospice at home	

				Long-term care facilities	
			Inadequate		Lacking the quality or quantity required; insufficient
			It is about money		
				Lack of funding	
				Medicare has limited coverage	
				TennCare does not pay enough	Hospice houses may not take TennCare because they will not get paid enough
				Hospice benefit is an outpatient benefit	The hospice benefit is for the service, not for room and board
				It is not profitable	
			Inaccurate claim		
				Not always a time constraint	Some claims of a two-week maximum are made
				There are hospice beds other places	There are more beds in other facilities, like hospitals and nursing homes
			Hospice is typically done at home		
			Lack of doctor referrals		There are not enough referrals to hospice to make residential hospice facilities profitable
			Other		
Problem Stream	9) In several national reports, Tennessee ranks in the bottom 20% in various areas of end-of-life healthcare, including palliative care and long-term services and support. Would you talk with me a little about that?	**National Ranking of Tennessee's End-of-Life Healthcare**			**What their thoughts are about Tennessee's low ranking in numerous areas of end-of-life healthcare on a national level.**
			Did not agree		Participant was surprised to hear this data
				Tennessee is improving	
				Thought we ranked higher	
			Agreed		Participant was not surprised to hear this data

				Lack of caregiver support	
				No state income tax	This impacts the funding that can go into areas of end-of-life healthcare
				Unhealthy population	Tennessee ranks nationally has having a very unhealthy population overall
				Religious state	Tennessee ranks nationally as one of the most religious states
				Lack of specialists in these areas	There is a lack of end-of-life healthcare specialists in Tennessee
			Data questioned		
				Accuracy	
				Subjective	
				Criteria	
			Other		
Problem Stream	10) Nationally, fewer than 10% of medical schools offer education on the process of death and dying to their students. Why do you think that is?	**Medical School Education**			**What can be done to increase the education on death and dying and other end-of-life healthcare issues in medical schools**
			The medical community		Includes individuals who are trained to practice medicine and/or work in healthcare
				Death avoidant	Death avoidance involves refusal to accept the certainty of death
				Trained to intervene	
				Supposed to prolong life	
				They see death as a failure	
				Doctors do not want to give bad news	
				It is not a priority	
			It is required now		
				May not be in effect yet	It could take time for medical schools to implement newly required curricula
			It is improving		

				Nurse practitioner programs	These programs are taking more of an active role in end-of-life healthcare education
				Oncology programs	These programs require more education in death and dying and end-of-life healthcare
			Unsure why		
				It should be an educational component	
				Hard to believe that statistic	
			We have to re-train		Doctors and patients have to learn to be honest and ask questions about prognosis
			Not true for all medical schools		
				Some teach more than others	Some participants referred to their own employers' curricula
			Lack of interest		
				Faculty	
				Students	
				Students going into specialties	There are very few medical students who are going into general medicine or areas of end-of-life healthcare
			Other		
Policy Stream	11) In your professional opinion, what could the state of Tennessee do to increase the use of Advance Directives?	**Advance Directives**			**Do they think there is anything that could be done in the state legislature to increase the use of advance directives in the state**
			Create awareness		Make people more aware about the existence and importance of advance directives
				Do more outreach	
				Public service announcements	
				Work with local businesses	
				Educate people	
			Require it		Make it mandatory for healthcare professionals to assist patients in completing an advance directive

				People over a certain age	
				People with specific medical issues	
				Have Goals of Care discussions	
			Involve State boards		There are many state boards involved in areas of end-of-life healthcare
				TELP	Tennessee End-of-Life Partnership
				Heath Facilities Licensing Board	
			Have one consistent form		This refers to the fact that there are numerous advance directive forms available
				Make it very clear	Make the document as simple as possible and easy to understand
				Have a designated place for it	This is done in other states, ex: put it in the freezer or under your mattress
			Have a state-wide initiative		
				Improves lives	
				Enhances patient autonomy	
				Replicate a good model	
			Get legislators interested		Educate legislators on the benefits of promoting advance directives in the state
				Saves money	Eliminating unwanted healthcare could save the state a lot of money
			Provide training		Help healthcare providers to develop the skills to have conversations about advance directives
			Tie it to specific activities		Attach information about advance directives to things that residents interact with regularly
				Driver's license	Create something similar to organ donation when someone gets their license
				Hospital discharge	Make it a mandatory process during every hospital discharge
			Determine responsibility		Who has the responsibility to promote the use of advance directives
				Hospitals	
				Medical institutions	

				Government	
				Individuals	
			Other		
Politics Stream	12) End-of-life healthcare policy can sometimes include controversial topics in medicine including removal of feeding tubes, refusal of treatments, discontinuing life support, and assisted dying. In fact, physician-assisted death has been legalized in 7 states, and Washington D.C. Will you share your thoughts about that?	**Controversial Topics**			**Where does the expert stand on areas of end-of-life healthcare that involve controversial topics like physician-assisted death**
			Oppose it		
				It is not appropriate to expedite death	
			Support it		
			Other		
Policy Stream	13) Physician-assisted death legislation has been proposed in Tennessee three times since 2015 (once in 2015 and twice in 2017). Both republican and democratic legislators have proposed this legislation? What are your thoughts on that?	**Physician-Assisted Death Legislation in Tennessee**			**Do they have any thoughts on the legislation that has already been proposed on assisted-dying in Tennessee**
			Was unaware		Did not know assisted-dying legislation had been proposed in Tennessee
			Was aware		Did know assisted-dying legislation had been proposed in Tennessee

				It is political	Assisted dying is a political issue
				Compared to abortion debate	
				Tennessee is conservative	
Politics Stream	14) What are your thoughts about assisted dying?	**Opinion on Assisted Dying**			**Are they for or against legalized physician-assisted death**
			Oppose it		
			Support it		
				It protects the physician	Assisted-dying legislation protects the physician from liability
				It protects the family	Assisted-dying legislation protects the family from liability
				Protects patient autonomy	Gives a person the right to decide for themselves what is best for them
			Unsure		
			Concerns		
				It involves too many other people	May deter people because of all the steps they have to take
				It should not be political	It should be what is best for the patient, not about political affiliation
				Legislators do not want to endorse it	Some compare it to endorsing HPV vaccines or birth control means it is okay to have sex
			Other		
Policy Stream	15) In your opinion, what are some of the most important things the state of Tennessee needs to do to improve the overall quality of end-of-life healthcare?	**Most Important Issues for Improved End-of-Life Healthcare in Tennessee**			**What are the most important things that can be done in Tennessee to improve end-of-life healthcare.**
			Need to follow quality measures		Quality measures are tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care.

			Need replicable models		Models that can be successfully reproduced once they have been created
			Education		
			Outreach		
			Research the Tennessee Certificate of Need issue		It is the policy of the state that "the establishment and modification of health care institutions, facilities and services, shall be accomplished in a manner that is orderly, economical and consistent with the effective development of necessary and adequate means of providing for the health care of the people of Tennessee."
			Increase advance directive use		An advance directive is a written statement of a person's wishes regarding medical treatment, often including a living will, made to ensure those wishes are carried out should the person be unable to communicate them to a doctor
				Make it less confusing	
				Encourage people to have one	
				Offer training to healthcare workers	
			Abandon capped benefits for healthcare		These caps are sometimes placed on particular services such as prescriptions, medical services, treatments, or hospitalizations
			Focus on community-based services		Care for all people who need health care assistance in their homes. An example of community-based health care is an-in hospice nurse program.
				Provide more at-home care	
			Improve caregiver support		
			Replicate the VA health system		
			Provide resources		Resources include funding and education among others
			More knowledgeable staff		Staff knowledgeable in areas of end-of-life healthcare
			More funding		Funding for various areas of end-of-life healthcare

			Have conditional grants		Grants that are conditional on certain end-of-life healthcare quality measures, such as advance directive completion
			Electronic health records		Digital versions of the paper charts in clinician offices, clinics, and hospitals. EHRs contain notes and information collected by and for the clinicians in that office, clinic, or hospital and are mostly used by providers for diagnosis and treatment
				Make progress on crosstalk	Sharing information between hospital systems and their electronic health records
Clarification	16) Is there anything else you would like to add?	**Final Thoughts**			**This gives the expert the opportunity to share anything they feel is important. It can include clarifying previous responses and/or adding new information**

Appendix G: Tier 2 Codebook

Impact Area	**Interview Questions**	**Node**	**Child Node**	**Sub-Node**	**Description**
Policy Stream	1) What areas of policy are you most passionate about?	**Policy Focus**			**The areas of policy that the legislator is most focused on, in any area of policy, not just healthcare**
			Children		
				Adoption	Adoption is a process whereby a person assumes the parenting of another
				Foster care	A temporary service provided by States for children who cannot live with their families
			Opioid crisis		An opioid crisis is the overuse or misuse of addictive opioid drugs with significant medical, social, and economic consequences, including overdose deaths
			Healthcare		
				Behavioral health	Can incorporate physical and mental struggles—eating habits, exercise routines, and alcohol consumption
				Public health	Public health promotes and protects the health of people and the communities where they live, learn, work and play
				Mental illness	Mental illness, also called mental health disorders, refers to a wide range of mental health conditions… disorders that affect your mood, thinking and behavior
				Rural healthcare	In medicine, rural health or rural medicine is the interdisciplinary study of health and health care delivery in rural environments. The concept of rural health incorporates many fields, including geography, midwifery, nursing, sociology, economics, and telehealth or telemedicine
			Education		
			Vulnerable populations		Vulnerable populations include the economically disadvantaged, racial, and ethnic minorities, the uninsured, low-income children, the elderly, the homeless, those with human immunodeficiency virus (HIV), and those with other chronic health conditions, including severe mental illness
				Disabled people	
				Elderly	
				Domestic abuse victims	
			Budgetary issues		
			Criminal justice		Criminal justice is the delivery of justice to those who have committed crimes
			Business		
			Societal problems		Any condition or behavior that has negative consequences for large numbers of people and that is generally recognized as a condition or behavior that needs to be addressed.

Policy Stream	2) Will you talk to me about what guides or shapes your decisions when you vote on policy? (Or… How do you make up your mind?) PROMPT: Personal? Moral? Religious? Personal experiences?	**Voting Decision Process**			**How does a legislator come to a decision on how to vote on a specific policy**
			Research		
				Data	
				Listen to arguments	Consider both sides of an issue
				Facts that are presented	
				Consult experts	
			Experiential		The process of learning through experience
				Life experiences	
				Political experiences	
			Morals		A person's standards of behavior or beliefs concerning what is and is not acceptable for them to do
				Do what is right	Is it the "right" thing to do?
				Vote their conscience	Means that they're ignoring practical politics and focusing on the moral issues
				Gut feeling	An instinct or intuition; an immediate or basic feeling or reaction without a logical rationale
			Principles		
				Personal	A personal or specific basis of conduct or management
				Political	A Constitutional basis of conduct. "Is it constitutional?"
			Future impact		
				Will it improve lives	
				Downstream consequences	What are the unforeseen consequences and effects
			Religious convictions		Does it align with religious beliefs.
			Constituents		Voters within an electoral district
				What they want	
				What they do not want	
			Impact on Tennessee		How will the legislation affect the state of Tennessee
			Other		
Clarification	3) When I say "end-of-life" healthcare, what do you think of?	**End-of-Life Healthcare Defined**			**How does the legislator define "end-of-life healthcare"**

			Palliative Care		Specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family
			Hospice Care		Care designed to give supportive care to people in the final phase of a terminal illness and focus on comfort and quality of life, rather than cure. The goal is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible
			Geriatrics		A branch of medicine that deals with the problems and diseases of old age and the medical care and treatment of aging
			Lifelong healthcare		Healthcare that starts the day you are born and continues throughout life
			Location of care		Where end-of-life healthcare is given. A physical location
				Hospital	
				Nursing home	
				At home	
				Long-term care facility	
				Residential hospice	
			Things missed		
				Missed opportunities	
				Missed experiences	
			Misunderstandings		
				Between doctors and patients	
				Between doctors and families	
				Between palliative and hospice care	
				About what palliative care is	
			Planning for future care		
				Talk about Goals of Care	Goals of care are the aims for a person's care, as agreed between him/her, his/her family, careers, and healthcare team. A person's goals of care are not always restricted to medical care. Goals of care in end-of-life healthcare will change over time, particularly as the person enters the terminal phase
				Long-term view of end-of-life care	

				Comfort Measures	Refers to medical treatment of a dying person where the natural dying process is permitted to occur while assuring maximum comfort. It includes attention to the psychological and spiritual needs of the patient and support for both the dying patient and the patient's family
				Quality of life	Quality of life (QOL) is related to symptoms, functioning, psychological and social wellbeing, and probably to a lesser extent to meaning and fulfillment
			Terminal Diagnosis		A disease or condition which can't be cured and is likely to lead to someone's death
				Life ending	A diagnosis that denotes impending death
				Life limiting	Life-limiting illness is a term used to describe an incurable condition that will shorten a person's life, though they may continue to live active lives for many years
			Time frame		
				Specific time frame	
				No time frame	
			Other		
Clarification	4) When I say "end-of-life healthcare *policy*, what do you think of?	**End-of-Life Healthcare Policy Defined**			**How does the legislator define end-of-life healthcare policy in contrast with their definition of what end-of-life healthcare is**
			Supporting individuals		
			Assisted dying		
				Physician-assisted death	Refers to a patient self-administering prescribed life-ending medication
				Euthanasia	Refers to a physician administering life-ending medication for the patient
			Hospice access		
			Access to medicine		The ability to obtain needed pain medication to reduce pain and suffering
			Specific legislation		
			Advisory councils		May also be referred to as a committee or board
			Health regulations		To make sure quality standards are being adhered to
			Patient rights		
			Other		
Politics Stream	5) Can you tell me about a time when you were conflicted about a vote? About whether you would vote for or against an issue?	**Conflicted About a Voting Decision**			**Has there ever been a time when the legislator was unsure about whether they would vote for or against an issue, and how did they navigate making a decision.**
			Yes		
				Nothing specific	

				On the health committee	
				Occasionally	
				Specific example given	
				"Shades of gray"	Every bill has some debate involved. Nothing is simply "black and white"
			No		
				Cannot think of one	
			Not often		
Policy Stream	6) During my interviews with end-of-life healthcare experts in Tennessee, there was a discussion about Advance Directives. One of the suggestions was for the legislature to promote a statewide initiative to promote them. What are your thoughts about that?	**Advance Directives Initiative**			**What are their initial thoughts on promoting a statewide initiative on advance directives**
			Unsure		
				Something should be done	
				Tennessee could do better	
			Cannot be mandated		A mandate is an authoritative command
				A healthcare issue	Advance directives are between a person and their doctor
			Education		
				Increase public awareness	
			Streamline the process		The act of altering an item to make it simpler or more efficient. For example, you can streamline advance directives by ensuring the steps in the process are consistent and repeatable, regardless of who is creating and using them
			It is a cultural issue		Different cultures have different patterns of behaviors and norms of living. Hence, what is acceptable in one culture is not necessarily acceptable in another
			Statewide initiative		Statewide engagement, education, and promotion
				Appropriate funding	
				Marketing campaign	
				Destigmatize advance directives	There is a stigma around advance directives because it involves death, dying, and end-of-life healthcare.
			Create policy		
				Steps taken	How is policy taken from an idea to reality

				Barriers	What are the things that will make the creation of policy difficult
			Other		
Policy Stream	7) A concern that was brought to my attention during my interviews with the experts, was the lack of family caregiver support in the area of end-of-life healthcare. In your opinion, what could the legislature do to address this?	**Caregiver Support Issue**			**What could the state of Tennessee do in the legislature to improve caregiver support**
			It is about money		
				Caregiver pay adjustment	
				A budgetary challenge	
				People cannot make a living	
				Change the reimbursement rates	For at home caregivers, adult daycare centers, and other assistance programs for at-home caregivers
			Give employment waivers		This would apply to people who have a non-violent crime on their record and want to work as a caregiver
			TN could do better		
				Improve caregiver support	
				Invest in home care	
				Assure good hospice at home	
				Replicate "best practices"	A best practice is a method or technique that has been generally accepted as superior to any alternatives because it produces results that are superior to those achieved by other means or because it has become a standard way of doing things
			Unsure		
				Hard to track	It is not easy to evaluate home caregivers and their needs
				Tough to answer	
				Cannot control family choices	If a family member does not want to be a home caregiver, they cannot be forced to do so by the state legislature
			Other		

Politics Stream	8) End-of-life healthcare policy can sometimes include controversial topics including removal of feeding tubes, refusal of treatments, discontinuing life support, and assisted dying. Will you share your thoughts about that?	**Controversial Topics**			**Where does the legislator stand on end-of-life healthcare policy that involves controversial topics like physician-assisted death**
			Oppose it		The legislator opposes physician-assisted death
			Support it		The legislator supports physician-assisted death
			Politics		These are controversial topics that can be polarizing
			Personal experience		Some legislators shared person stories relevant to this question
			Other		
Clarification	Is there anything else you would like to add?	**Final Thoughts**			**This gives the legislator the opportunity to share anything they feel is important. It can include clarifying previous responses and/or adding new information**

VITA

ERIN ELIZABETH MAUCK

Education:

Doctor of Public Health (DrPH) – Community and Behavioral Health, College of Public Health, East Tennessee State University, Johnson City, Tennessee, 2020

Master of Arts (MA) – Sociology
College of Arts and Sciences, East Tennessee State University, Johnson City, Tennessee, 2016

Bachelor of Science (BS) – Sociology, Minor: Biology
East Tennessee State University, Johnson City, Tennessee, 2014

Professional Experience:

Graduate Research Assistant, College of Public Health; Tennessee State University (2017 – 2020)

Field Placement, Hospice and Palliative Medicine; James H. Quillen VA Medical Center (August 2018 – May 2019)

South Carolina Women’s Study – Choose Well Project 2, Lab Manager and Retention Coordinator; East Tennessee State University (August 2017 – May 2019)

Community Organizer – Community Organizing in Public Health, One Acre Café (Spring 2019)

Research Assistant – Applied Social Research Lab; East Tennessee State University (2016 – 2017)

Tennessee Poll Co-Researcher, East Tennessee State University (2015 – 2016)

Research Assistant - Tennessee Community Crime Reduction Program (TCCRP); East Tennessee State University (2013)

Research Assistant - Johnson City Community Health Center (JCCHC), East Tennessee State University (2013)

Publications:

Mauck, E., (2016). Oregon’s Death with Dignity Act: Socially Constructing a Good Death. Master’s Thesis.

Mauck, E., Foster, K. (2016). The Tennessee Poll finds that “End of Life Choices” is an Emotionally Charged Topic among Tennesseans. East Tennessee State University_ padrelease.

Honors & Awards:

Outstanding Doctor of Public Health Student Award – Community and Behavioral Health, College of Public Health, East Tennessee State University (2020)

Featured researcher in ETSU’s School of Graduate Studies’ *Illuminated* magazine (2020, 2015)

Outstanding Doctor of Public Health Student Award – Community and Behavioral Health, College of Public Health, East Tennessee State University (2019)

The Honor Society of Phi Kappa Phi Inductee, East Tennessee State University chapter (2016)

The Golden Key International Honor Society Inductee, East Tennessee State University chapter (2016)