

Rural Appalachian Person and Family Decision Making at End of Life

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Mary Lou Clark Fornehed
August 2017

Copyright© 2017 by Mary Lou Clark Fornehed
All rights reserved.

Dedication

For my Daddy, the late Erbie Bethel Clark, Jr. who always believed and encouraged me to the very end. He seemed to understand my struggle and determination with doctoral work and knew the right thing to say at the right time...he had such wisdom, and I miss him very much. I know he was very proud of me and this dissertation research certainly speaks to the personal struggle we had as a family at the end of my Daddy's life. I can only hope that his legacy will reach out to help others struggling with the same EOL crisis.

Acknowledgments

I would like to first say how grateful and humbled I have been by the kind and trusting rural Appalachian relationships I have encountered during this time of doctoral study. I could not have completed such meaningful research without everyone's help.

From the bottom of my heart, I thank my committee chair and advisor, Dr. Sandra Mixer for her patience and willingness to share her transcultural knowledge, her endless hours of discussions, and the meaningful mentoring that has helped me to transition from a Ph.D. student to a nursing scholar. I also want to thank Dr. Lisa Lindley for all her mentoring and willingness to share her knowledge of Hospice and end of life care. I am also very grateful for the time and expertise of my two other committee members, Dr. Tami Wyatt and Dr. Annette Mendola. It has truly taken a village to reach this point and without them, I would have been lost.

I also want to say how grateful and thankful I have been to have a wonderful husband, Olle Fornehed, son, Jonas Fornehed, Mother, Brenda Clark, special friend, Bill Powell, sister, Leah Wilson, brother-in-law Lane Wilson, nephews Clark and Jack Wilson and my dearest friend Jeri Lynn Baker. They love me with all their hearts and have been the most wonderful encouragers who stayed with me until I reached the finish line. They have made me laugh, kept me from crying when that was all I wanted to do, allowed me to cry when it was just the only thing left to do, and they hid the dull butter knives. For them, I am deeply grateful.

I would like to acknowledge my friends and colleagues at Tennessee Technological University School of Nursing. They have understood the struggle like no one else could and for their encouragement, I am very grateful.

Another acknowledgement I must make is that of the kind and gracious encouragement from my community public library. White County Public Library staff fed me food and drink, provided me with a quiet place to work on many, many occasions, and always had a smile on their face. I feel truly blessed to be able to call these people my neighbors and friends. For them I am so grateful.

I must say thank you to the Cookeville Regional Charitable Foundation for their graciousness with a monetary award to assist with my dissertation research. For your belief in my doctoral work, I am very grateful.

Lastly, I want to acknowledge how thankful I am for God who has loved me and cared for me through my life. I am the most grateful for Him.

Abstract

The dynamics of delivering care to persons at end of life (EOL) have dramatically changed in the last twenty years. Improved management of chronic illness and provision of aggressive life sustaining measures for an illness once deemed fatal are more common, significantly increasing longevity. While it is estimated that more than 40 million persons with life-limiting illness worldwide are candidates for some form of palliative or end-of-life care (EOLC), less than 14% of them will receive it.

When coping with life-limiting illness, people and their families are asked to make many complex and difficult decisions about EOL, palliative, or hospice care. The role a family chooses to play at EOL is reflected in the cultural expressions, patterns, and practices they use to help make meaning from the life-limiting illness and subsequent death of the family member. The purpose of this qualitative ethnonursing study was to discover and describe the culture care expressions, patterns, and practices that influence rural Appalachian families when making decisions at EOL. The goal is to discover generic and professional care that supports rural Appalachian families to make decisions that help them receive culturally congruent EOLC. Interviews with 10 key and 15 general informants provided in-depth examination of the culture of rural Appalachians within the context of family decision making (FDM) at EOL. Guided by the theory of Culture Care Diversity and Universality and the ethnonursing research method, four themes were discovered:

- Theme 1 – Rural Appalachians make EOL decisions with family,
- Theme 2 – Communication encompassing EOL FDM is essential and complex,
- Theme 3 – Education and economics influence FDM at EOL, and

- Theme 4 – The need for comfort for living while dying.

The study provided important insight into the EOL decision making experience for rural Appalachians which may ultimately improve access to palliative and hospice care for this underserved population, thereby contributing to a dignified death for persons with life limiting illness and their families. Recommendations for nurses and other interdisciplinary team members may reduce health disparities for rural Appalachians and promote meaningful culturally congruent EOLC.

Keywords: Ethnonursing research method, end of life care, Culture Care Theory, communication, hope, comfort, faith

Table of Contents

Chapter One: Introduction	1
Domain of Inquiry	4
Purpose	4
Research Questions	4
Orientational Definitions	5
Background and Significance	11
Theory of Culture Care Diversity and Universality	18
Chapter Summary	21
Chapter Two: Literature Review	22
Review of Literature Process	22
Ethnohistory of the Rural Appalachian People	24
Summary of Ethnohistory Literature	39
End-of-Life Literature	41
Chapter Summary	54
Chapter Three: Methodology	56
Ethnonursing Research Method	56
Data Collection	58
Data Analysis	62
Chapter Summary	66
Chapter Four: Findings	67
Ethnodemographics	67
Ethnohistory	68
Themes of Rural Appalachian Family Decision Making at End of Life	72
Nursing/Interdisciplinary Team Decisions and Actions	81
Chapter Summary	83
Chapter Five: Discussion	85
Contribution to Nursing Theory	85
Professional Care Practice and Policy Implications	91
Recommendations for Future Research	95
Reflections of the Study	95
Limitations	96
Conclusion	96

List of References	98
Appendices.....	120
Vita	176

List of Tables

Table 1. Patterns and Quotes for Theme 1	123
Table 2. Patterns and Quotes for Theme 2	126
Table 3. Patterns and Quotes for Theme 3	131
Table 4. Patterns and Quotes for Theme 4	134
Table 5. Recommended Nursing/Interdisciplinary Team Decisions and Actions	136

List of Figures

Figure 1. Depiction of the end-of-life care continuum and illness trajectory	121
Figure 2. Map of the 40-county informant recruitment area	122

Chapter One: Introduction

The dynamics of delivering care to persons at end of life (EOL) has dramatically changed in the last twenty years. Improved management of chronic illness and provision of aggressive life-sustaining measures for an illness once deemed fatal are more common, increasing longevity significantly (National Institutes of Health [NIH], 2014; National Institute of Nursing Research [NINR], 2013). It is estimated that more than 40 million persons with life-limiting illness worldwide are candidates for some form of palliative or end-of-life care (EOLC), however, less than 14% of them will receive it (World Health Organization [WHO], 2015).

EOLC terminology often is used interchangeably with care given to people with life-limiting illness. The meanings of this terminology also have changed over time and according to the culture within which it is discussed. The EOL transition has never been fully defined from a scientific standpoint because of poor prognostication of death by healthcare providers (NIH, 2004). The last stages of life are seen as components of a complex trajectory that is influenced by the disease process itself, the age and gender of the person who is dying, his/her culture and beliefs, as well as the person's dependence on others (NIH, 2004; NINR, 2013).

When considering how EOLC is defined, one must examine the trajectory of care for life-limiting illness. EOLC has been described as being a component of palliative and hospice care. It further is described as care that addresses the social, emotional, spiritual, and physical well-being of a person with life-limiting illness from diagnosis to death and through bereavement (Coyle, 2015; Institute of Medicine [IOM], 2014). Palliative care is defined as an approach that focuses on quality of life. Curative or

aggressive care may continue during the provision of palliative care (Coyle, 2015; IOM, 2015; Izumi, Nagae, Sakurai, & Imamura, 2012). When a person's life-limiting illness progresses to a prognostication of death within approximately six months or less hospice care may begin. In EOLC, the focus on alleviation of suffering and quality of life continues (Izumi et al., 2012; National Hospice and Palliative Care Organization [NHPCO], 2015a).

When coping with life-limiting illness, people and their families are asked to make many complex and difficult decisions about EOL, palliative, or hospice care (Wallace, 2015a). In this context, *families* includes the person with the life-limiting illness and those considered significant in their lives (e.g. spouse, children, stepchildren, siblings, partner, close friends, etc.) that together create a unit of care (Medicare Payment Advisory Commission, 2015; Steele & Davies, 2015). The role a family chooses to play at EOL is reflected in the cultural expressions, patterns, and practices they use to help make meaning from the life-limiting illness and subsequent death of the family member (Mazanec & Panke, 2015). Benefits of culturally supportive FDM at EOL include effective symptom management, less disruption during the transition to EOLC, reduction of the patient's and families' stress when making EOLC decisions; a dignified death for the person with life-limiting illness; and strengthened faith with the possibility of diminished grief during the bereavement period (Bužgová & Sikorová, 2015; Dose, Rhudy, Holland, & Olson, 2011; Embler, 2012; Hess, 2013; Howe, 2014; Izumi et al., 2012; Melhado & Byers, 2011; Mixer, Fornehed, Varney, & Lindley, 2014). Many persons near death are unable to share in EOL decision making with their family members because of cognitive impairments related to their illness process and/or

sedating medications. Therefore, family members often are placed in the role of surrogate decision maker for the patient (Melhado & Byers, 2011).

Receiving a diagnosis of a life-limiting illness can be frightening and families have the right to make EOL decisions that are congruent with their cultural expressions, patterns, and practices (Mazanec & Panke, 2015). However, in rural areas, there often are barriers to EOL decision making for persons who are often older, seriously ill, and have fewer economic advantages than people have in other regions (Rural Health Information Hub, 2016). Such barriers influence the EOLC options that are available to families when making decisions about managing life-limiting illness. Discovering the culture care expressions, patterns, and practices of rural Appalachian families who are facing EOL decisions is research science that is supported by both the NINR (2014) and NIH (2014).

Similar to people from other regions of the country, rural Appalachian persons with life-limiting illness prefer to die comfortably at home (Mixer et al., 2014). In the east Tennessee region of Appalachia, hospice use ranges as low as 16% in rural areas and as high as 55% in urban areas compared to 45% nationwide (Centers for Disease Control and Prevention [CDC], 2015; Mixer et al., 2014; NHPCO, 2015a). In general, rural Appalachian persons have little medical knowledge, distrust medical personnel, and seek faith healing when faced with life-limiting illness (Brown & May, 2005; Mixer et al., 2014). Within the Appalachian culture, people honor family and place faith at the center of their lives, such practices lead to Appalachians generally being hopeful for their loved one's recovery (Brown & May, 2005; Mixer et al., 2014).

Although rural Appalachians desire to be cared for at home by their families at EOL, few make decisions to access EOLC. Discovering the cultural expressions, patterns, and practices of rural Appalachian FDM at EOL can support persons with life-limiting illness and their families and contribute to them having a higher quality of life and a dignified death (Blinderman & Billings, 2015; Izumi et al., 2012; NIH, 2014).

Domain of Inquiry

The domain of inquiry for this study is guided by the Theory of Culture Care Diversity and Universality (CCT) and ethnonursing research method (Leininger 2002a; Wehbe-Alamah & McFarland, 2015a). As defined in the CCT, the domain of inquiry is the “succinct, tailor-made statement focused directly and specifically on culture care and health phenomenon” (Leininger 2002b, p. 92). The domain of inquiry for this study is the culturally congruent expressions, patterns, and practices of rural Appalachian FDM at EOL.

Purpose

The purpose of this qualitative ethnonursing study is to discover and describe the culture care expressions, patterns, and practices that influence rural Appalachian families when making decisions at EOL. The goal is to discover emic (generic/folk) and etic (professional) care that supports rural Appalachian families to make decisions that help them receive culturally congruent (CC) EOLC.

Research Questions

The following research questions guided this study of rural Appalachian families engaging in decision making at EOL.

- What are the culture care expressions, patterns, and practices that influence

rural Appalachian families' decision making at EOL?

- How do the worldviews, cultural and social structure, environmental context, and ethnohistory influence rural Appalachian FDM at EOL?
- What are the emic (generic) and etic (professional) care practices that influence rural Appalachian FDM at EOL?
- What culture care nursing actions would support rural Appalachian FDM at EOL?
- What culture care interdisciplinary team actions would support rural Appalachia FDM at EOL?

Oriental Definitions

Oriental definitions are central constructs from the CCT that were inductively determined from previous research. The oriental definitions selected for this study were chosen to reflect the domain of inquiry and research question concepts.

Oriental terms and definitions are intentionally broad as they evolved further during the discovery of rural Appalachian families' cultural expressions, patterns, and practices related to decision making at EOL (McFarland, Mixer, Wehbe-Alamah, & Burk, 2012; Wehbe-Alamah & McFarland, 2015a).

End of Life and End-of-Life Care

The concepts of EOL and EOLC are inextricably intertwined. Poor prognostication by healthcare providers as well as cultural similarities and differences complicate the concept of EOL, making it difficult to determine when the process of dying begins. For many who have life-limiting illness, death comes quickly. However, for many individuals the dying process progresses at a much slower pace (Izumi et al., 2012; NIH, 2014). To complicate the issues further, the terms EOL, EOLC, palliative

care, and hospice care are used interchangeably. EOLC is defined by the NIH (2014) as complete care for a person with a life-limiting illness with the goals of comfort and quality of life leading up to the person's death. For this study, EOLC is defined as the supportive and holistic care provided to dying persons and their families in the hours, days, weeks, or months prior to the person succumbing to a life-limiting illness (Figure 1, Appendix A).

Hospice Care

Hospice care is the provision of care for terminally ill persons, a concept first used in the 1940s in London, England (NHPCO, 2015b). Introduced in the U.S. in the 1960s, hospice care has evolved to include compassionate care for persons (and their families) with life-limiting illness whose life expectancy is less than six months. Hospice includes spiritual and emotional support, pain and symptom management, and interdisciplinary care (Grant & Scott, 2015; NHPCO, 2015a). The emphasis of hospice care is not curing the life-limiting illness, but rather helping the patient and family experience the best quality of life possible and death with dignity. Most insurance companies cover hospice care that includes durable medical equipment and medications related to the terminal illness. Hospice care offers volunteer support and provides bereavement services for up to 13 months after the person has died. Care may be provided in the home, acute care setting, long-term care setting, or at a freestanding Hospice center (Figure 1, Appendix A).

Palliative Care

The WHO (2015) defines palliative care as the assessment and treatment of physical, spiritual, or psychosocial problems of a person with life-limiting illness and

their family. Relieving suffering and providing comfort and support are the primary goals of the interdisciplinary team providing this care. With palliative care, the emphasis on symptom management remains throughout the illness process, even as curative care is either continued or withdrawn. While palliative care and EOLC may overlap, they should not be seen as synonymous, as palliative care is not just care at EOL (Izumi et al., 2012). Therefore, for the purposes of this study, palliative care will include care throughout the illness trajectory from diagnosis of the life-limiting illness, through EOLC (Figure 1, Appendix A).

Rural Appalachian Persons

Rural Appalachian persons live in a unique region of the U.S. that stretches from northern Mississippi, extending both north and east to southern New York, encompassing 13 states and 420 counties (Abramson & Haskell, 2006; The Appalachian Regional Commission, 2016). Those living in this area have long been mythologized as mountain folk who are socially and physically isolated from the rest of the U.S. by geography, culture, and economy (Coyne et al., 2006). The rural Appalachian persons participating in this study live in the 40 county region of eastern Tennessee (Figure 2, Appendix A).

Family Decision Making

For the purposes of this study, families included the person with the life-limiting illness and persons deemed significant in their lives (e.g. spouse, children, stepchildren, siblings, partner, close friends, etc.) that together create a unit of care. The role a family chooses to play at EOL is reflected in the cultural expressions, patterns, and practices they use to help make meaning from the life-limiting illness and subsequent death of the

family member (Mazanec & Panke, 2015). When rural Appalachian families are facing decisions about a loved one's EOLC, Wallace (2015a) discussed the need to consider the impact that culture has on family decisions. Rural Appalachian family members tend to be loyal to each other and when a family member becomes gravely ill, final decisions are generally made after all options are discussed with extended family (Burkett, Mulcahy, & Zahorik, 2006).

Culture Care and Culturally Congruent Nursing/Interdisciplinary Care

Culture is defined by Leininger (2006a) as the "learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular culture that guides thinking, decisions, and actions in patterned ways and often intergenerationally" (p. 13). Culture care is an action or practice that can be either etic (professional) or emic (generic/folk) and assists rural Appalachian persons and families receive culturally congruent EOLC (adapted from McFarland & Wehbe-Alamah, 2015, pp. 9-10).

Culturally congruent care (CCC) is satisfying, meaningful, and beneficial care that fits with peoples' daily lives and, in this study context, helps them face EOL (Leininger, 2006a; Mixer et al., 2014). Culturally congruent nursing/interdisciplinary care honors the rural Appalachian person and their family when making decisions at EOL. This responsive and sensitive care incorporates appropriate nursing/interprofessional care actions that are meaningful to the person and family and grounded in the rural Appalachian culture (adapted from Leininger, 1997, p. 38; McFarland & Wehbe-Alamah, 2015, p. 7). Interdisciplinary team members might include nurses, clergy members, social workers, case managers, physicians, clinical pharmacists, ethicists, and others involved in EOL decision making.

Generic Care

Generic care that facilitates or supports persons and families at EOL consists of traditional or local folk knowledge and practices that are shared and learned among the rural Appalachian culture. Emic views are insider views or the view from the rural Appalachian perspective (adapted from McFarland & Wehbe-Alamah, 2015, p. 14). These views might include traditional, folk, lay, home, local, or alternative care practices at EOL (adapted from Leininger, 1997, p. 36). These cultural practices of the rural Appalachian family are relied upon for FDM at EOL.

Professional Care

Professional care is nursing and/or interdisciplinary care that is provided for rural Appalachian persons and their families, and facilitates and supports culturally congruent decision making at EOL. Etic views are outsider views or the view from the healthcare provider's perspective that influence and explain the health, well-being, or dying of rural Appalachian persons (adapted from McFarland & Wehbe-Alamah, 2015, p. 14).

Culture Care Decision and Action Modes

To provide culturally congruent care, Leininger proposed three decision and action modes that could enable nurses to use creative approaches when caring for patients (adapted from Leininger, 2006a, p. 8). These three modes are (a) culture care preservation and /or maintenance, (b) culture care accommodation and /or negotiation, and (c) culture care repatterning and /or restructuring. Culture care preservation and/or maintenance refers to assistive, supportive, facilitative, or enabling decisions and actions that help nurses/interdisciplinary team members preserve or maintain EOL decision-making expressions, patterns, and practices for the rural Appalachian and their

family (adapted from McFarland & Wehbe-Alamah, 2015, p. 16). Culture care accommodation and/or negotiation refers to assistive, supportive, facilitative, or enabling professional actions and decisions that help rural Appalachian persons and their families adapt to or negotiate with others to make culturally congruent decisions at EOL (adapted from McFarland & Wehbe-Alamah, 2015, p. 16). Culture care repatterning and/or restructuring refers to those assistive, supportive, facilitative, or enabling professional decisions and actions that help rural Appalachian persons and their families reorder, change, or greatly modify their decisions at EOL (adapted from McFarland & Wehbe-Alamah, 2015, p. 16).

Environmental Context

The environment is a major construct of the theory. The environment is not only a geographical location but also includes the human actions and decisions within a particular setting or situation that give meaning and order to cultural expressions, patterns, and practices (Leininger, 1997). For rural Appalachians and their families, the environment generally includes being isolated from a geographical perspective, while still being in close relationships with family and friends (Burns, Scott, & Thompson, 2006). The discovery of the environmental context in this study contributed to the understanding of the expressions, patterns, and practices for decision making at EOL for the rural Appalachian and family (adapted from McFarland & Wehbe-Alamah, 2015, p. 15). For example, key informants discussed out-migration within their family that—because of a lack of knowledge about the illness trajectory of the person dying—influenced decision making at EOL by creating a barrier to hospice referral care.

Background and Significance

The NIH (2004), in conjunction with the NINR (2013), supports research about EOL issues. Recent reports from the IOM (2014) provide substantial evidence indicates family-oriented and patient-centered EOLC provides symptom relief for individuals with life-limiting illness and supports the quality of life of patients and their families. In order to provide supportive, culturally congruent care to dying rural Appalachian individuals and their families, the expressions, patterns and practices they use when making EOLC decisions must be discovered.

The Appalachian Mountains stretch more than 1000 miles along the eastern coast of the U.S. including 13 states from New York to Mississippi's Natchez Trace (MacAvoy & Lippman, 2001). Appalachian people have unique worldviews that define their cultural and social dimensions and traditions. Their values and beliefs include valuing strong social and family ties, self-reliance, pride, love of the mountains where they live, working hard, and maintaining strong moral values (Coyne, Demian-Popescu, & Friend, 2006; Lee, 2012; Mixer et al., 2014). Geographically, rural Appalachian people live in an impoverished and medically underserved area, with limited access to medical care (U.S. Department of Health and Human Services [USDHHS], 2016).

In the east Tennessee region of rural Appalachia, 40 counties (Figure 2, Appendix A) are deemed medically underserved (USDHHS, 2016b) and health provider shortage areas (USDHHS, 2016a). Poverty is widespread in this area, with approximately 21 % of rural Appalachians in these counties being at or below poverty level, as compared to 17.6 % of Tennessee residents and 15.4% nationwide (Appalachian Regional Commission, 2013; U.S. Census Bureau, 2015b). Several

factors—limited education, diminished health literacy, and rural and mountainous geographic terrain—make it difficult for this vulnerable population to access EOLC services (Bakitas, Clifford, Dionne-Odom, & Kvale, 2015; Carlson, Bradley, Du, & Morrison, 2010; Coyne et al., 2006; Mixer et al., 2014).

Rural Appalachians in eastern Tennessee have the basic human right to seek and receive EOLC, as set forth by the United Nations (2011) in the Universal Declaration of Human Rights. The EOLC care they receive should be informed by their cultural expressions, patterns, and practices. For example, Lee (2012) studied Appalachian women and children who were living in a homeless shelter. Her study, guided by the CCT and ethnonursing method, viewed this vulnerable and marginalized population through the emic lens and examined the meanings and experiences of family homelessness and its influence on health. She discovered that, while respectful care was vital to these families, they faced many cultural challenges and frequently felt disrespected.

The rural Appalachian honors the family unit, with many decisions regarding health and EOLC made as a family unit (Brown & May, 2005; Mixer et al., 2014). When patients and families must cope with life-limiting illness, the decision to begin EOLC is often the most difficult one they make (Wallace, 2015a). While family roles for day-to-day decision making may be well defined, formal family roles generally are not culturally defined in any population (Quinn et al., 2012). Quinn and colleagues used ethnography to describe family members' informal roles when EOLC decision making was initiated in the intensive care unit. They found many informal roles evolved during the decision-making process. Researchers concluded that it is necessary for healthcare providers to

employ strategies that accommodate these informal roles to facilitate FDM and ensure a smooth transition to EOLC.

While evidence supports the important role of FDM in the rural Appalachian culture when addressing life-limiting illness, there is little known regarding the culture care needs of the family when making EOLC decisions. Guided by the CCT, the findings from this study contributed to the discipline of nursing by providing a better understanding of the culture care expressions, patterns, and practices and care actions that promote culturally congruent decision making for EOLC.

Across the nation, the culture of healthcare focuses on extending life as reflected in the trends of increased ICU admissions and aggressive treatment of life-limiting illnesses (NIH, 2014; NINR, 2013; Schreibeis-Baum et al., 2016). Despite conflicting literature indicating more persons are dying at home (National Center for Health Statistics, 2010), Teno et al. (2013) reported that more persons are being admitted to an ICU prior to death, being hospitalized 90 days prior to death, and transitioning to home or a skilled nursing facility with an average of three or fewer days of EOLC in 2009.

These factors resulted in the population spending an average of three days or fewer in EOLC in 2009. NHPCO (2015a) reported that dying patients spent an average of seven days or less in hospice care in 2014. While persons with life-limiting illness and their families may have viewed those few days at home as beneficial in terms of symptom management, and emotional, spiritual, and bereavement support, it is not known what the family or caregiver experienced when making care decisions, if persons' culture was acknowledged, if their care was planned to meet their needs at EOL, or if they were given dignity in death (Campbell et al., 2009; Lynch, 2013; Riffin et

al., 2015; Schreibeis-Baum et al., 2016). EOLC, such as hospice care, can be delivered at home, in an acute care setting, or in a long-term care facility.

This study has significance for rural Appalachian families at EOL because they generally lack access to high-quality palliative and hospice care services. The Medicare Payment Advisory Commission (2015) reported that only 26% of hospice care units were located in rural areas. This fact presents many challenges for this population including having a lack of family members to care for a dying person at home, needing to travel long distances for care, and having trouble with Medicare reimbursement. In addition, access is often limited because many rural providers lack EOL-educated healthcare providers, which is complicated by the fact that geographically remote persons often have low healthcare literacy and therefore need more assistance (Bakitas et al., 2015; Campbell, Merwin, & Yan, 2009; Carlson et al., 2010; Coyne et al., 2006; Mixer et al., 2014; Robinson et al., 2009; Schreibeis-Baum et al., 2016). This study provided important insight into the EOL experience of rural Appalachian people with the goal of ultimately improving access to palliative and hospice care for this underserved population.

This study has significance for EOLC clinicians because many are unfamiliar with the type of services rural Appalachians need at EOL and lack the practical and cultural EOLC knowledge need to care for these patients (Lynch, 2013; Schreibeis-Baum et al., 2016). No research was found about how persons in rural Appalachia and their families make decisions at EOL, either as a family unit or in conjunction with an interdisciplinary EOLC team. The literature does indicate there are poor communication and a lack of shared decision making between the family and interdisciplinary care team that can lead

to the provision of unwanted, aggressive elder care in ICUs instead of EOLC (Dillworth et al., 2016; Heyland et al., 2015). With physicians generally serving as the gatekeepers for hospice services, and Appalachia being an underserved healthcare provider area (USDHHS, 2016b; Wallace, 2015b), there may not be enough physicians in the area to refer these patients to appropriate EOLC (Campbell et al., 2009). Culture and ethnicity is perhaps the leading determination of how persons and families view EOLC.

Generally, Western culture sees EOLC decision making as a process performed by autonomous individuals who are focused on their quality of life (Coyle, 2014; Lynch, 2013). Culturally, rural Appalachians often maintain that families be included in all decisions when a person has a life-limiting illness. It is important that clinicians recognize these differences when discussing EOLC care with these patients and their families. While there was no known quantitative research to predict rural Appalachian utilization of EOLC services, such as hospice care, research findings have shown a disparity in rural Appalachians' use of these services compared with other minorities. It is possible that rural Appalachians do not readily access hospice care because of their cultural beliefs (such as their distrust of strangers and strong spiritual beliefs) and a lack of referrals from a physician pool with deficient cultural knowledge about rural Appalachia (Lynch, 2013).

This study has significance for EOLC policy because such policy needs to be changed to reflect the fact that, in general, the rural Appalachian population has significant healthcare illiteracy and is uninformed regarding palliative care options (Schreibers-Baum et al., 2016). A major knowledge barrier cited in the literature was the interchangeable use of EOL terminology, with most persons believing that hospice care

is focused on dying rather than living, thus limiting the demand for these services. Robinson et al. (2009) refers to the care providers in rural areas as generalist professionals with palliative care being provided to only a miniscule portion of their patient population. The extremely limited use of palliative care in this region has made it difficult for providers to focus on the constantly changing knowledge and skills needed to help persons and their families make decisions at EOL. Medicare restricts hospice care access for patients who chose to continue curative care for life-limiting illnesses, thus limiting the palliative care options available to these patients (Wallace, 2015b) such as palliative radiation, chemotherapy, and intravenous nutrition. Rural Appalachian persons and their families' frequently continue aggressive curative care since stopping these therapies, even at EOL, is seen as giving up and losing faith in God's curative nature (Behringer & Krishnan, 2011; Shell & Tudiver, 2004). With such restrictive hospice care policies, many rural Appalachians unable to access palliative care experience poor symptom control, more hospitalizations, and poor quality of life. In contrast to the current care model, two counties included in this study (Hamblen and Knox) are participating in a new care initiative that is testing a payment and service delivery model called the Medicare Care Choices Model (Centers for Medicare & Medicaid Services, 2016b). This pilot care model is evaluating the quality of life, care received, and costs incurred by Medicare and Medicaid recipients in 140 U.S. cities. The program is testing the idea that providing curative care in conjunction with hospice-like support to these persons and their families will result in improved quality of life and reduced Medicare costs.

This study has significance to EOLC economics because not only is providing the

wrong type of care (aggressive, curative care when palliative/hospice/EOLC is more appropriate) is detrimental and not cost effective. The current healthcare system structure fails to incentivize proactive and coordinated care for persons with life-limiting illness and their families, resulting in barriers that prevent patients from obtaining the right care at the right time (Schreibers-Baum et al., 2016). In any population, the gold standard for palliative care is a patient-centered, culturally appropriate plan made by an interdisciplinary team that includes and supports the family. Such plans decrease the use of inpatient healthcare services by persons with life-limiting illness (Bainbridge, Seow, & Sussman, 2016; Bekelman et al., 2016; Colaberdino, Marshall, DuBose, & Daitz, 2016; Robinson et al., 2009). Achieving this gold standard is not common in rural settings that have limited access to interdisciplinary palliative care teams. For providers to be reimbursed for hospice care, the ill person must be deemed as having six months or less to live and forego curative treatment. If rural Appalachians chose to forego their hospice benefit, there are few options for appropriate EOLC that support both person and family, leading to a significant economic burden for those who wish to die at home (Essue et al., 2015; Robinson et al., 2009). Because of these reimbursement problems, hospice consults often are made late in the dying process (Lynch, 2013), resulting in increased ICU admissions and the continued provision of aggressive curative treatment in the last days of life, which leads to higher EOLC costs (Garrido, Prigerson, Bao, & Maciejewski, 2016), shortened hospice stays, and a large gap in EOLC services (Teno et al., 2013). In fiscal year 2017, the Centers for Medicaid & Medicare will begin new quality measures for Medicare-certified hospice centers (Centers for Medicare & Medicaid Services, 2016a). Two of these measures address the treatment preferences,

beliefs, and values desired by the dying person and their family. If these quality measures are not met, there will be a 2% reduction in Medicare payment to the hospice provider. The knowledge discovered in this study could help inform hospice care providers of the cultural values and beliefs used in FDM regarding EOL treatment in rural Appalachia.

The researcher has lived in rural Appalachia her entire life. She also has worked as an Acute Care Nurse Practitioner, where one of her primary roles is to communicate with people and their families about EOLC decisions. The researcher has continually observed rural Appalachians and their families struggle with making decisions at EOL. The process requires much support from family members, close friends, faith leaders, and the interdisciplinary team.

Theory of Culture Care Diversity and Universality

Leininger (Leininger, 1997, p. 4; McFarland & Wehbe-Alamah, 2015) developed the culture care theory (CCT) to study human phenomenon and discover transcultural nursing knowledge. The theory asserts that nurses can provide culturally congruent care only when the culture care expressions, patterns, and practices of people are known. The goal of the theory is to discover culturally congruent care that contributes to people's health and well-being or helps them face disabilities or dying.

Theoretical Framework

The epistemology of the CCT is that care is the essence of nursing (McFarland & Wehbe-Alamah, 2015). The CCT ontology speaks to care as nursing, health, curing, and well-being. Human care gives dignity to people and inspires them to get well and help others. Leininger purported that "there can be no curing without caring, but caring

could exist without curing” (Leininger, 2006a; McFarland & Wehbe-Alamah, 2015, p. 4).

The CCT was developed from Leininger’s philosophy of life; anthropologic experiences and knowledge; extensive nursing experience as a mental health nurse with children of diverse cultures; and spiritual insight that a superior being created all humans. Leininger used naturalistic inquiry to discover different aspects of care and culture in natural settings. Ontologically, Leininger contended that human experience is holistic and complex and that a person’s view of reality is determined by how they viewed events through their individual lenses or biases. Epistemologically, meanings in human experiences are derived from an understanding of a person’s social, economic, political, cultural, linguistic, and physical environments. Those who have the experiences are the most knowledgeable about these specific environments (Leininger, 1997; McFarland & Wehbe-Alamah, 2015).

Theoretical Tenets

A central principle of the CCT is that there are both commonalities and differences among cultures (Leininger, 1997; McFarland & Wehbe-Alamah, 2015). This tenet serves as the basis for beginning the process of developing transcultural knowledge for nurses. Critical influencers of culture care predict the patterns by which a culture defines illness, heals, and faces death. These influencers include a person’s view of where they are in the world as well as social and cultural factors, ethnohistory, environmental context, language, and both emic (general) and etic (professional) care. The CCT maintained that emic and etic health factors within different cultural contexts greatly influence health and illness outcomes. The theory includes three major action and decision modes that are predicted to provide culturally congruent care: (a) culture

care preservation/maintenance, (b) culture care accommodation/negotiation, and (c) culture care repatterning/restructuring. Integrating knowledge of a persons' culture into recommendations using these modes can help caregivers provide culturally congruent care.

Theoretical Assumptions

CCT theoretical assumptions, derived from CCT tenets, guide researchers in studying cultures over time and in different contexts and geographical locations. The following six assumptions, derived from 11 of Leininger's CCT theoretical assumptions, guided this research study (McFarland & Wehbe-Alamah, 2015):

1. Culture care is the essence of nursing care and the central, dominant, distinct, and unifying focus of EOL decision making for rural Appalachians and their families (adapted from assumption 1, p. 8).
2. Culture care is essential for humanistic EOL decision making when rural Appalachians and their families face the transition from curative to palliative to EOL care (adapted from assumption 2, p. 8).
3. Culture care expressions, patterns, and practices of rural Appalachians families' decision making at EOL are influenced by and embedded in their worldview, social structure factors (i.e., "religion, philosophy of life, kinship, politics, economics, education, and cultural values" (McFarland & Wehbe-Alamah, 2015, p. 8) as well as the ethnohistorical and environmental context (adapted from assumption 6, p. 8).
4. The rural Appalachian culture of decision making at EOL has discoverable generic (emic) and professional care (etic) practices that can be used to provide

culturally congruent support to these dying patients and their families (adapted from assumption 7, p. 9).

5. Leininger's three theoretical modes of care offer new, creative, and different therapeutic ways to help rural Appalachian families with decision making at EOL (adopted from assumption 9, p. 9).
6. The CCT and ethnonursing method offer an effective way to discover largely embedded, covert, epistemic, and ontological culture care knowledge regarding decision making at EOL for rural Appalachian and their families (adapted from assumption 10, p. 9).

Chapter Summary

The culture needs of rural Appalachian families making decisions for loved ones at EOL are not known. Generalizing these culture care needs hinders nurses and other interdisciplinary caregivers to provide appropriate, supportive care to this unique population. To address this knowledge gap and promote a dignified death within the rural Appalachian culture, the supportive culture care needs of rural Appalachians making EOL decisions must be discovered, described, and disseminated.

Chapter Two: Literature Review

The literature review process was approached from both an emic (generic/folk) and etic (professional) perspective while focusing on the study's domain of inquiry. Findings included classical and current literature about rural Appalachian ethnohistory, including their worldview and the cultural and social structure dimensions of (a) kinship and social factors, (b) economic and educational factors, (c) religious and spiritual factors, and (d) cultural values, beliefs, and lifeways. EOL literature examines death and dying in the healthcare setting as well as in the rural Appalachian community. Finally, the culture care expressions found in the EOL literature focus on FDM, ethics, and spirituality and the role each plays in the EOL process. Within the context of culture care, this literature review provides an overview of rural Appalachian expressions, patterns, and practices. As with any cultural group, there is diversity and therefore this review of literature is not intended to stereotype this population.

Review of Literature Process

The scholarly literature search was initially conducted on CINAHL, Web of Science, and PubMed using the terms EOL and rural Appalachia, which produced only a few unusable articles. The researcher conducted another search using just the term EOL that produced hundreds of articles. Combining EOL with key words—such as culture, Appalachia, ethics, rural, family, decision making, and ethnohistory—yielded approximately 190 key peer-reviewed research and anecdotal articles from the past 15 years that were relevant to this study's domain of inquiry. After the researcher read all potential abstracts, she filed them under the primary theme she had assigned to each. All article citations were placed in EndNote. The researcher then searched the articles

for classical authors and seminal pieces of work. Next, the researcher used Google and Google Scholar to retrieve the individual pieces of work. This process revealed several resources that proved invaluable for this study: the WHO, Appalachian Regional Commission, NIH, NINR, CDC, NHPCO, and the USDHHS. As part of the research team from the previous rural Appalachian study, the researcher recalled a book of literature about rural Appalachia and EOL issues that also proved to be an important resource.

An extensive literature review was conducted to discover the ethnohistory of the rural Appalachian people, including their traditions and healthcare culture. Web of Science, ERIC, and CINAHL were used and approximately 140 peer-reviewed articles were retrieved. A review of the abstracts revealed approximately 20 peer-reviewed anecdotal and research articles (dating from 1975 to 2015) that appeared relevant for describing the ethnohistory of the rural Appalachian people. These articles provided facts about the rural Appalachian families' communities, cultural traditions, health institutions, health risks, religion, education, and death and dying concerns.

The Sunrise Enabler (Appendix B) was used to examine the major tenets of the theory within the unique and complex culture of rural Appalachia (Wehbe-Alamah & McFarland, 2015b). This enabler served as the researcher's guide for considering the multiple influencers of culture and care within this community and conducting the ethnohistory research literature review. The Sunrise Enabler also was used as a reference when searching for literature that revealed relevant influencers specific to this study's domain of inquiry: culturally congruent care of the rural Appalachian family when decision making at EOL.

Ethnohistory of the Rural Appalachian People

The Appalachian region includes 13 states and 420 counties that span 205,000 square miles (Appalachian Regional Commission, 2016). This vast region is one of contrasts, starting at the southernmost mountains of New York and continuing south to northern Mississippi. Initially dependent on mining, forestry, and agriculture, Appalachia has become more diverse over the past 50 years to include manufacturing and service industries. However, because of its vastness, the economic status of the Appalachian region varies from county to county and includes remote areas with widespread poverty. The Appalachian region includes eastern Tennessee, where this study was conducted. The eastern portion of rural Appalachia is remote and continues to have widespread poverty and limited access to healthcare, which are in stark contrast to other regions of the country.

The eastern rural Appalachia family culture is dynamic, complex, diverse, and rich. Some common characteristics include humility, modesty, rugged independence, prideful, and having love of family, community, and nature. Rural Appalachians generally are distrustful of outsiders and often are misunderstood and stereotyped as being 'stupid,' 'hillbillies,' and 'rednecks' (Coyne et al., 2006; Huttlinger, 2013; Mixer et al., 2014; Salyers & Ritchie, 2006). A medical student doing his rotation in rural Appalachia made a poignant observation: "My Yankee accent and my formidable shirt and tie made it clear I was an outsider. It took more than one coal miner covered in soot in the exam room, more than one duct-taped puncture wound before I realized that such sights were commonplace... One day... I offered up to a patient that I had married a girl from their county and from that time on, it all changed. I was welcomed into the fold as

family... To be an insider in Appalachia is to be tied to the people. For them, community is everything” (Carter, 2009, p. 470).

While southern Appalachia was thought to be isolated and difficult to traverse, Stephenson (1984) noted that much of the migration to the western U.S. in the 1700s and 1800s was by people of European descent and occurred through the southern portion of rural Appalachia. It was thought that people wanting to escape South Carolina’s mosquitos and malaria were drawn to the easternmost part of Tennessee. For the many settlers who stayed and called rural Appalachia home, there was a sense that the area’s isolation and ruggedness gave them a feeling of being free from the persecution they experienced in their previous homes over religious, social, and economic differences (Gobble, 2009). In modern times, while some infrastructure improvement has taken place, Appalachia remains a mountainous, rugged region with a unique culture. Rural Appalachians distrust outside influences, cherish the solitude of their environment, stay close to family, and maintain a fundamental spirituality based mostly on Pentecostal doctrine. These religious beliefs lead rural Appalachians to take the Bible literally, thereby believing there are both God and the devil, and good and evil are not abstract concepts but tangible entities. Rural Appalachians may aspire to live pure lives, believing that the devil causes sickness in impure people (Gobble, 2009). Other denominations in rural Appalachia also profess belief in an active Holy Spirit that can be accessed through prayer to heal some illnesses.

Family has always been an essential part of rural Appalachian culture (Burns et al., 2006). Family and kinship groups support each other economically, socially, emotionally, educationally, and often serve as the origin of personal identity in rural

Appalachian communities. Many families living in small rural communities have histories that extend back for hundreds of years, with many rural Appalachia persons demonstrating personal knowledge and connections to local histories. Because of this strong generational family bond, many older rural Appalachians who become ill are taken care of in an older adult child's home, a practice that helps create family stability and improve the quality of family life. Even with a healthcare crisis and life-limiting illness, decisions generally are made only after the immediate family members have consulted and discussed options with extended family members (Burkett et al., 2006).

Community, religion, place, economics, and government are major cultural themes that have long been known to affect the history of education in rural Appalachia (DeYoung, Glover, & Herzog, 2006). The education provided in community or church schools or community centers certainly evolved from the key factors of religion and morality. From the very beginning, rural Appalachian education usually included teaching Christian morality with the Bible as the textbook of choice. Early in the migration history, many rural Appalachian families were geographically dispersed, making it difficult if not impossible to establish a school system beyond a one-room schoolhouse or church school. The late 19th century ushered in the beginnings of school consolidation, an effort that was contested by many Appalachian families. From a cultural perspective, many Appalachians also did not believe in educating children beyond the 8th grade, as that might create a child to "get above their raisin" (DeYoung et al., 2006, p. 1518). To finance education in rural Appalachia and improve student competency in the 20th century rural Appalachians must begin to support schools,

especially in light of the number adults leaving the small communities to find improved opportunities outside of their mountain hollows (Gotts & Purnell, 1986).

In summary, the literature reveals an ethnohistory of the Eastern Tennessee rural Appalachia as a culturally diverse and geographically remote area (Appalachian Regional Commission, 2016). Family is the backbone of the rural Appalachian community, where churches and schools are created so people can worship and learn (DeYoung et al., 2006). While solitude has long been cherished, families form kinship groups and very ill individuals often are cared for by close kin and community members (Burkett et al., 2006). While it is known that family members confer with each other before making decisions for persons with life-limiting illnesses, we do not know how or in what cultural context these decisions are made.

In her review of the literature, the researcher initially focused on the worldview, and culture and social structure factors that influence the care of rural Appalachians. The literature review provided valuable cultural knowledge that helped the researcher be culturally sensitive during research process.

Worldview

The rural Appalachian worldview has historically included limited contact with the world beyond the mountain hollow and distrust of outsiders (Gobble, 2009). This combination of beliefs creates strong and complex kinship/community networks that included a heightened sense of caring for and being loyal to family. This perspective shapes how they view, understand, and express their physical, mental, and spiritual needs in this world. Death is considered a part of living and, because of their faith in God; they believe they will spend eternity with their deceased loved ones.

The values of family cohesiveness and being neighborly helped shape rural Appalachians' view of death. Death was common for the rural Appalachian, with diseases and accidents occurring frequently (Hufford, 2006). When rural Appalachians left the "front porch," (Lozier & Althouse, 1975, p. 7) this was a sign to the family and community that death likely was imminent. A gathering at the bedside then began and continued until the person either returned to health or died. The women in the family would prepare the body for burial and the men of the community would build the coffins and dig the graves. These death rituals have changed little over the years in rural Appalachia. The gathering at the bedside may now be at a hospital or nursing home instead of at the individual's home. After death, the body now goes to a funeral home to be prepared for burial. Visitation by family and friends still occurs, but at the funeral home. The community still cares for the family of the deceased in a neighborly way.

In recent times, rural Appalachia has seen migration both into and out of the mountains and small communities (DeYoung et al., 2006; Phipps, 2006). Out-migration was by rural Appalachian seeking a better life through more education and better employment. The increase of returning rural Appalachians may be due to persons originally from the area retiring to live close to what they consider their home. In rural Appalachia, men have historically been the family providers while women stayed home to raise children and care for ill or dying family members (Gobble, 2009).

Rural Appalachian's unique language reflects the notion that they are "person oriented" (Lewis, Messner, & McDowell, 1985, p. 23) and tolerant of differences among the population. For example, they may say an elderly person with a life-threatening problem is just "getting older" (p. 23). This view can result in many rural Appalachian

persons presenting to a healthcare provider with a serious illness that cannot be healed. This population also may use folk medicine prior to seeking outside healthcare, a practice that can lead to serious illness.

Historically, the use of alternative or emic (folk) medical practices by rural Appalachians was common and the practice continues today (Hufford, 2006; Presley, 2013). This traditional healing worldview comes from knowledge, originating with early settlers that were passed down from generation to generation through the spoken word. Home remedies using botanicals, animal, and mineral substances are still common in the area. Professional healthcare providers who present a negative view of such practices can create more distrust of the medical profession in the rural Appalachians they serve.

Cultural and Social Structure Dimensions

The eastern Tennessee region of rural Appalachia is unified by its culture, landscape, and complex history (Abramson & Haskell, 2006). In the past 30 years, many parts of Appalachia have witnessed urbanization, improved infrastructure, a growing economy, less unemployment, and improved healthcare. However, Appalachians in rural eastern Tennessee have continued to struggle, as their physical surroundings and poverty level have remained largely unchanged (Appalachian Regional Commission, 2013; U.S. Census Bureau, 2015c). The researcher will discuss the dynamic, holistic, and interrelated patterns of the many factors that influence the lifeways of the rural Appalachian persons: kinship, social, economic, educational, religious and spiritual, language, and communication.

Kinship and social factors. Rural Appalachian persons often refer to their family members and neighbors as *kin*. An anthropologist examining semantics and kinship in rural Appalachian communities found that kinship was often referred to as a “set” (Batteau, 1982, p. 18). The kin set is used to describe the family units as they are geographically connected within communities. Kin sets include persons who are descendants of an original settler and still live in close proximity to one another. These communities are very often within the valleys or “hollers” of the mountains that often follow a stream or river. These kin sets offer support to one another in good and bad times, often deeding land to children and grandchildren so additional households can begin, thereby extending the kin set (Burns et al., 2006).

The kin set is the “fundamental unit of organization” (Burns et al., 2006, p. 170) for the rural Appalachian family. Historically, these families followed traditional family roles that continue today with some minor changes. In a traditionally patriarchal family unit, the father is the provider and the mother stays home to care for the dependent children. In modern families, the mother may now work outside the home while retaining the position of caregiver and household manager. Many families have had to become flexible within their traditional roles in order to survive. Many people have out-migrated beyond rural Appalachian borders to survive financially. In such cases, extended family or kin sets often step in to provide the support necessary during temporary job loss or illness (Burns et al., 2006; Lozier & Althouse, 1975; Salyers & Ritchie, 2006).

As of year 2010 rural Appalachian adults 65 years and older constitute 16% of the population, compared to 11.5% in the remainder of the state of Tennessee (Pollard & Jacobsen, 2011). Within the rural Appalachian community, the elderly hold a special

place of honor, are cared for by other family members or kin sets, and usually are treated with great respect (Burns et al., 2006; Lewis et al., 1985). Due to poverty, cultural hesitation, mistrust of outsiders, and the geography of the rural areas in which they live, healthcare delivery often is complicated. Historically, rural Appalachian elders are strongly attached to their communities, families, and homes. This makes the decision of whether to out-migrate in order to be with family and receive care extremely difficult (Salyers & Ritchie, 2006).

Community gatherings are common social events where rural Appalachians play, worship, visit, make music, and share personal and family stories (Burns et al., 2006). Traditional gathering places that still exist today include country stores, the family's front porch, or barber shop. Some of these gatherings, such as quilt making groups, are symbolic of this region. All community gatherings serve social and economic functions by promoting cultural traditions that might be otherwise lost, fostering relationships among the community members, and providing a mechanism for welcoming and orienting new community members.

Economic and educational factors. The labor that has historically shaped the economics of rural Appalachia is complex and reflected the class and diversity of the region as well as work relations and capitalism (Hennen & Lewis, 2006). Capitalism is discussed in conjunction with physical work as far back as the 1800s, suggesting that the farmers had some access to markets for which goods and services were exchanged for the materials needed to survive. Rural Appalachians employed diverse farming management practices in order to make a living. Farming was usually a partnership between the men and the women. Initially, the landscape, hollows, adequate water

supply, and great Appalachian forest certainly promoted agriculture practice during the 1800s (Burns et al., 2006). However, the Civil War left farms barren, many with only the wives to manage during a time of great economic distress. Land development and deforestation has left some productive farmland difficult to use. In fact, the number of farmable acres decreased by 12 million from 1969 to 1997 (Best & Wood, 2006; Colyer, 2001). In modern times, these challenges have left many rural Appalachian agricultural families no choice but to work off-farm in order to make ends meet. While women sometimes had to leave the farm and home to become a second wage earner, these positions usually extended from their work at home (Bishara, 1987). It has also been suggested that these demographic and economic changes have left the aged of the area, especially women, more vulnerable economically (Rowles & Johansson, 1993). However, the effects of this situation are thought to be buffered by informal support systems and close-knit kin set members who feel responsible for caring for elderly family members. Some rural Appalachian retired people believe that, if they are in good standing with the community, they should receive support until death (Lozier & Althouse, 1975).

Even off-farm work producing goods and services involved more than just commodity production (Hennen & Lewis, 2006). Historically, off-farm labor included mining, millwork, or logging. Labor issues such as unemployment, taxes, race, ethnicity, and the environmental destruction resulting from this work influenced the expressions of rural Appalachians' values and beliefs. Coal mining shaped the eastern Tennessee Appalachian landscape and population. Immigration of persons from other countries to work in these mines was common, creating unfamiliar diversity within the community

and leaving many Appalachians without jobs. Mining jobs were not unionized in rural Appalachia, leaving many struggling to survive. While unions eventually came to the mining communities in the 1930s, the continued strife and low wages continue even into this century.

The education received in rural Appalachia in the 21st century is guided by policies and procedures established at the Tennessee state and federal level (DeYoung et al., 2006). These policies have presented problems, as few are culturally sensitive or address the actual needs of some of the rural Appalachian counties. Rural Appalachia is in crucial need of policy reform to address the educational needs of its students (The Rural School Community and Trust, 2014). Without policy reform, rural Appalachian instructional salaries and expenditures per student will continue to be low. There also has been much debate about consolidating some schools and using bus transportation, which could mean very long travel times for children. Rural Appalachian cultural marginalization has always been present because of old stereotypes of being a “hillbilly” and “stupid,” many of which have persisted due to the region’s economic distress and poverty. The cultural marginalization of this area has had a significant impact on the type of careers rural Appalachian students aspire to and choose (Ali & McWhirter, 2006; Ali & Saunders, 2009). Rural Appalachian adolescents receive mixed cultural messages from their peers regarding their educational advancement. Additionally, the historical presence of mining and manufacturing employment in these small communities has often led to the belief that education is not necessary. Adolescent confidence for a better life lags in rural Appalachia due to the decrease in manufacturing and mining jobs and the message from family members who undervalue education. These influences

can leave these adolescents poorly prepared to join an evolving workforce that demands education beyond a high school diploma (Ali & Saunders, 2009; Hendrickson, 2012). Young people who are unprepared and unambitious contribute to the cycle of poverty in this area.

Religious factors. In rural Appalachia, there are several characteristics common to most religious practices. The most basic characteristic is the belief that “God is the controlling force in life” (Dorgan, 2006, p. 1283). Other characteristics that have remained mostly intact in the area over the years include the belief that clergy are called and trained by God, religion and faith are part of life whether or not a church is attended, every event is in God’s hands, people have little control over outcomes (fatalism), faith in God goes beyond religion, and faith is the basis for most decisions and actions in life (Campbell & Ash, 2007; Diddle & Denham, 2010; Dorgan, 2006; Rowles, 1991).

Fatalism among rural Appalachians has been identified in the literature as a barrier to both seeking and receiving healthcare. Behringer and Krishnan (2011) and Shell and Tudiver (2004) discussed the barriers of fatalism to both cancer screening and caring for cancer patients. When rural Appalachians profess having a personal relationship with God and the belief that their health is under God’s control, they may believe that having cancer likely is a death sentence, regardless of whether they were screened or treated for the disease.

There is minimal literature to substantiate the religious beliefs at EOL of rural Appalachians either from a historic or modern perspective. In their qualitative research Campbell and Ash (2007) and Mixer et al. (2014) discovered that rural Appalachians

believe that faith in God was of the utmost importance, as only God knew when death would come.

Language and communication factors. The seemingly archaic nature of the language and phrases of rural Appalachian people have long been ridiculed by those living outside the community (Montgomery, 2006). While the unique language patterns are considered regional, there is no single dialect, which can make communication with outsiders even more difficult. There has been much debate regarding the linguistic ancestry of the language, but with the influx of European immigrants and the American Indians, the speech is felt to be of mixed origin.

Language clashes between rural Appalachians and outsiders have led to frustration when communicating needs becomes necessary (Carter, 2009; Diddle & Denham, 2010; Lozier & Althouse, 1975; Rowles, 1991; Salyers & Ritchie, 2006). Appalachians employ many different tactics, along with speech, to communicate their needs. Historically, retired rural Appalachians communicated with their community by sitting on the front porch and meeting people at their home rather than at work, meeting the family's immediate needs (Lozier & Althouse, 1975). Persons from rural Appalachia often must leave the region to seek employment or care for ailing family members. However, leaving can result in anxiety due to guilt from leaving extended family in Appalachia, the love of the beauty of where they live, and the fearfulness of being able to assimilate in another area (Salyers & Ritchie, 2006). It can take a while for persons from rural Appalachia to get to the crux of what they are trying to communicate. When speaking with members of this population about their healthcare needs, it is important to

find a common language and allow adequate time for them to discuss the issues at hand.

Prayer was found to be a common form of communication within the rural Appalachian community. Health-related prayer requests often were seen as informal ways to communicate with God for assistance in healing the sick (Simpson & King, 1999). Prayer also was a way of communicating and staying connected with the community at a time of need. Member of this population often form prayer chains to ask for assistance for a list of persons or ask for symptom management in a time of discomfort (Burkhardt, 1993; Campbell & Ash, 2007).

When considering healthcare culture in rural Appalachia, effective communication is imperative. The lessons learned from persons who are not from rural Appalachia have improved the understanding of the importance of finding ways to communicate effectively. When individuals caring for the ill and dying are not from the area, they generally are considered outsiders. In order for providers to be considered trusted caregivers, they need to find a way to create a path to the “inside” of the family (Campbell & Ash, 2007; Carter, 2009; Lewis et al., 1985; Rowles, 1991). The introduction of foreign healthcare providers to the region to offset the health labor shortage (Appalachian Regional Commission, 2016) makes healthcare communication even more difficult for rural Appalachians. This practice also may make it less likely that rural Appalachians’ healthcare needs will be met in a culturally satisfactory way.

Healthcare Expressions, Patterns, and Practices

This study will focus on the specific problem of FDM about dying in rural Appalachia. Therefore, the researcher felt it was important to search the literature for

both research and anecdotal literature regarding general healthcare expressions, patterns, and practices of rural Appalachia. As already discussed, in many ways healthcare has changed very little in this rural area where the lack of access to healthcare persists due to geography and a dearth of providers (USDHHS, 2016a). Traditional healthcare decisions and actions continue to be guided by a fatalistic belief that God is in charge of the rural Appalachian's health and there is little they can do to change the outcome (Behringer & Krishnan, 2011).

Health-related decisions usually are made at the last minute and for acute problems only. This population may seek medical care from a healthcare professional only as a last resort (Coyne et al., 2006; Shell & Tudiver, 2004). Literature points to several cultural reasons for delaying or managing care in rural Appalachia: initial reliance on emic or folk care to treat illness, a fatalistic view of disease, a day-to-day view of living, distrust of healthcare professionals, language barriers, lack of medical knowledge, and the concern that family problems will become community knowledge (Coyne et al., 2006; Lewis et al., 1985; Shell & Tudiver, 2004).

It is discouraging that minimal research in the last five years reports significant disparities in cancer and drug overdose deaths, type 2 diabetes mellitus, and cardiovascular disease risk factors in rural Appalachians (Campbell, Boyer, Campbell, & Rovnyak, 2012; Carpenter, 2015; Paskett et al., 2011; Saleh et al., 2015). However, these findings are accompanied by recommendations for providing culturally appropriate care for rural Appalachians as well as educational suggestions for the healthcare professionals who care for them.

Holistic Health, Illness, and Death

As evidenced by numerous previous references, the rural Appalachians in eastern Tennessee live mostly a day-to-day existence (i.e., focusing on the here and now instead of the future), seek care only for acute problems, and leave little time to schedule office visits to manage or discuss health screenings or chronic disease management (Coyne et al., 2006; Presley, 2013; Rowles, 1991). A fatalistic view of many health issues has led the rural Appalachian to feel that their “sickness was the will of God” (Rowles, 1991, p. 379), a view that links their religion strongly to their healthcare, reports that this fatalistic view is a barrier to cancer screening (Shell & Tudiver, 2004) as rural Appalachians generally see cancer as a death sentence. However, rural Appalachians tend to be faithful even when facing a life-limiting illness. Their connection with God through prayer was a mechanism for receiving symptom relief, feeling hope, staying connected with family and their community, and gaining a source of strength while going through the dying process (Campbell & Ash, 2007).

Generic (Folk) and Professional Care Practices

The “folk” worldview is the lens rural Appalachians use to view relationships between themselves and their environment (Hufford, 2006). Their worldview of their natural environment, formed by their Native American and European ancestors, is that the land is a perfect “manifestation of God” (p. 862). Historically, rural Appalachians have been leery of receiving care from outsiders, and have used folk medicine remedies before seeking traditional healthcare (Lewis et al., 1985). Folk medicine likely is a combination of traditional healing practices that have been acquired from many different cultures. Folk medicine practices have been passed from generation to generation over

the centuries (Hufford, 2006). Animal, plant, and mineral substances all have been used to treat illness according to theories of sickness from as far back as the eighteenth century. These treatments often are referred to as home remedies. Folk healers were sought out because they were trusted individuals, known to all within the community, and able to speak the language of rural Appalachians (Lewis et al., 1985; Rowles, 1991).

Appalachian individuals placed minimal emphasis on seeking outside medical help, preventative care, or assistance for managing chronic problems, and instead initially sought folk wisdom for any acute problem. Rural Appalachians reported folk illnesses—such as “bold hives” or the “nerves”—that were not recognized by traditional healthcare professionals (Hufford, 2006). Such language could prove difficult for an outsider attempting to provide care to understand. The elderly of rural Appalachia continue to embrace the folk medicine culture (Rowles, 1991). However, the following factors have led to growing acceptance of a slowly changing health culture that combines professional and folk care: progress in the integration of healthcare professionals into the community, improvement in culturally appropriate communication with care recipients, and increased understanding of the culture by healthcare professionals (Ahijevych et al., 2003; Barish & Snyder, 2008; Presley, 2013; Rowles, 1991; Schoenberg et al., 2015).

Summary of Ethnohistory Literature

In summary, the literature reveals that the rural Appalachia of Eastern Tennessee remains essentially unchanged in its physical surroundings and extreme poverty (Appalachian Regional Commission, 2013). Within communities, people often

refer to their neighbors as *kin*. Family units, called kin sets, offer each other loyalty and support in good and bad times (Batteau, 1982). In this traditionally patriarchal society, women generally care for the sick until they return to health or die (Burns et al., 2006). Death is seen as a part of life and they are reassured by their faith in God that they will spend eternity with their deceased loved ones.

The economics of rural Appalachia are complex and diverse with a combination of family farming, manufacturing, and mining. Modern times have resulted in many families leaving their community in order to survive (Hennen & Lewis, 2006). Because of the need to contribute economically to the family, children historically were educated in small schoolhouses only to the 8th grade. Twenty-first century education in rural Appalachia now is guided by state and national policy (DeYoung et al., 2006). However, with low pay for teachers and little value placed on education by the community as a whole, children often are not encouraged to seek a secondary education, contributing to the continuing cycle of poverty (Ali & Saunders, 2006).

The literature also revealed that most rural Appalachian persons believe God is in control of every aspect of their lives, with religion and faith being significant whether or not they attend church (Dorgan, 2006). Their faith in God serves as the basis for most decisions, with fatalism still posing a significant barrier to both screening and caring for ill rural Appalachians (Behringer & Krishnan, 2011). Rural Appalachians, especially the elderly, believe that God is in control of their health regardless of how they care for themselves, a belief that may be considered a form of fatalism. Another complicating factor is the fact that the language of the rural Appalachians may be difficult for those living outside to understand (Montgomery, 2006). Prayer also is a

common form of communication in this region. During prayer, rural Appalachians may ask God to heal the sick. Prayer chains also may be used to help community members stay connected with each other.

Health decisions are typically made at the last minute with many seriously-ill rural Appalachians presenting to their provider only as a last resort after using traditional folk care remedies (Coyne et al., 2006). In such cases, providers often are seen as untrustworthy outsiders and the language barrier may hinder communication. Folk medicine often is continued because rural Appalachians' view the natural environment as the manifestation of God.

One study revealed that rural Appalachians often want to combine folk and professional care at EOL (Mixer et al., 2014). While having close family nearby and practicing religious and spiritual traditions creates comfort in times of illness, rural Appalachian individuals need the ability to communicate their healthcare needs along with the cultural belief that both folk and professional care are important in their everyday decisions and actions. However, there is no literature that reveals how the rural Appalachian's worldview and social and cultural factors inform or assist these families in making decisions for their loved ones at EOL.

End-of-Life Literature

EOLC and the ability of families to make appropriate decisions for this care can be a complex process. While there has been an increase in EOL research funding, much work still needs to be done. The NINR (2013) and the IOM (2015) have continued to identify gaps in EOL research. Increased research and publication in cultural EOL and palliative care needs, family caregivers' roles in the EOL process, and ways to

avoid unwanted and unbeneficial care remains important research priorities. Emerging themes covered in this EOL literature review are death and dying, rural Appalachian culture and death, FDM at EOL. The subthemes were ethics and spirituality and how these factors influenced FDM at EOL.

Death and Dying

There are two fundamental facts that create difficulty for persons with life-limiting illness who are facing the end of their lives. “First is the widespread and deeply held desire to not be dead. Second is medicine’s inability to predict the future...when death is the alternative, many patients who have only a small amount of hope will pay a high price to continue the struggle” (Finucane, 1999, p. 1670). Whether a person and their family are facing serious life-limiting illness, decreasing independence, and approaching death, or the family is grieving the loss of a loved one, a continuum of EOLC should be available for all communities and cultures (NINR, 2013) (Figure 1, Appendix A). The IOM (2014) reported that the advancement of medical treatments and technologies that can sustain the dying and prolong life are accompanied by collateral damage. These damages include but are not limited to a growing elderly population with chronic illness, a growing population diversity for which care assumptions cannot be made, high costs for EOL procedures that persons may not want or be able to afford, a lack of access to social services for which the dying could benefit, and barriers to care for disadvantaged persons and their family.

For most, death will not come suddenly but rather will result from a steady decline over years, months, or weeks because of chronic problems that will eventually become life limiting. Death may come after many transitions throughout this decline in

health, which may include multiple hospitalizations and long-term care facility stays. In their 2000–2009 quantitative study of persons over the age of 65 years, Teno et al. (2013) reported that these individuals are being increasingly admitted to intensive care units, and have increasing late transitions to hospice care in the last three days of life. Such transitions may involve a lack of care coordination for the person and family and no implementation of needed social services, both of which can create distress (Dose et al., 2011; IOM, 2015; Krishnan, Williams, & Maharaj, 2015). These troublesome and unwanted transitions may occur because of ineffective insensitive miscommunications with the dying person and their family.

Very few people are comfortable talking about death. This topic is avoided for several reasons including the fact that talking about death evokes feelings of loss and a reminder of human mortality (NIH, 2014). Death is a part of living and a process every person will face. Therefore, death should be discussed, especially in the context of healthcare needs and desires. Poor prognostication of death makes it difficult for families to make decisions that align with what the dying person wants, and can result in the provision of inappropriate and or low-quality care (IOM, 2015; Myatra et al., 2014; NIH, 2014). Advance discussions among family and friends regarding needs and wants at EOL is crucial because many persons are physically and cognitively impaired at EOL, making it virtually impossible for the dying person, family, and perhaps members of the interdisciplinary team to discuss EOL care. Another reason individuals' EOL care desires are not known is that such discussions are not always initiated by the interdisciplinary team, leaving the family to ponder the appropriate action while the person is in the last stages of dying (Hjelmfors et al., 2015; IOM, 2015). However, even

when EOLC discussions have taken place, families can still find these complex and emotional decisions difficult to make and may welcome support from the interdisciplinary team (Daly & Matzel, 2013; Huff, Weisenfluh, Murphy, & Black, 2006; IOM, 2015).

Across the U.S., more and more persons and their families are facing decisions at EOL. Whether palliative care is provided in the home, an acute care setting, a freestanding hospice facility, or a long-term care facility, underserved rural communities have less access to this type of care (Campbell et al., 2009; NHPCO, 2015a). Lynch (2013) and Bakitas et al. (2015) described barriers to palliative care in rural areas including those related to geography, healthcare system eligibility, workforce limitations, education deficits, and culture value differences. Although palliative care research in rural locations is in its infancy, Schreibeis-Baum et al. (2016) found in a qualitative study that some barriers to care seem to be universal to rural areas. These barriers include lack of palliative care knowledge among healthcare providers, cultural beliefs regarding palliative care, lack of public understanding of the issue, and the need for changes in reimbursement. Interdisciplinary palliative care teams can help bridge these care gaps within the rural communities. In a qualitative study, Armstrong, Jenigiri, Hutson, Wachs, and Lambe (2012) examined patient and family palliative care satisfaction after discharge from a rural Appalachian community hospital where they were cared for by an interdisciplinary palliative care team. The team was rated “excellent to very good” (p. 383) in the following areas: communication, symptom management, providing individualized care, assisting in coping with EOLC, being respectful of the families, meeting person’s treatment wishes, and discharge planning.

In rural Appalachia, death was common because of disease, infant mortality, and accidents (Hufford, 2006). In part because of a lack of healthcare facilities and providers, rural Appalachians developed the cultural traits of family cohesiveness and neighborliness. When a person was known to be dying, the practice of a deathwatch would begin. Family and neighbors would sit with the ailing person until they either recovered or died. The area of rural Appalachia where this study will take place continues to be geographically isolated and medically underserved (Coyne et al., 2006; USDHHS, 2016a, 2016b). Fatalism is a cultural belief that persists in the area to this day (Huttlinger, 2013). Because of this belief, it is very common for persons to feel that life-limiting illness is the will of God and not seek healthcare until the symptoms are advanced. This belief emerged in a qualitative study as a barrier to rural Appalachians having routine cancer screenings (Shell & Tudiver, 2004). In their qualitative study, Coyne et al. (2006) also described how rural Appalachians view disease and accidents as an everyday part of their lives and therefore sought healthcare later rather than earlier. In another study “divine help for healing” (p. 4) through prayer was found to be help enough for many sick individuals.

In times of illness and death, clergy often are called (Hufford, 2006; Huttlinger, 2013). A “steadfast faith in God” (Coyne et al., 2006, p. 4) is a common theme expressed by those facing a life-limiting illness. Campbell and Ash (2007) described the experiences of Appalachian African Americans living with and managing life-limiting illness. Keeping the faith was an overarching theme these participants used to affirm their life, bond with their family and friends, and connect with God and themselves. Faith

was described as a fundamental form of support in the transition through the EOL process in this CCT/ethnonursing study.

In summary, medical advancements, including aggressive interventions for life-limiting illnesses, have changed the landscape of dying. Many care transitions can lead to the provision of inappropriate and unwanted care for dying persons (Teno, 2013). Everyone deserves quality EOLC. Unfortunately, many persons with life-limiting illness have had few discussions regarding their wishes for EOL. Even when family knows an individual's wishes, they may not be able to grant them due to the emotionally fraught and medically complex nature of the situation (Hjelmfors et al., 2015; IOM, 2015). Research results from the literature show that interdisciplinary palliative care providers can be supportive when decisions for EOLC need to be made. The rural Appalachian culture of strong family and neighbor ties can support individuals in times of illness and death. In addition, their strong faith in God as the ultimate healer may provide additional support during such trying times (Coyne et al., 2006). However, there is no literature to inform the healthcare provider how these families can be culturally supported and assisted in decision making at EOL.

Family Decision Making

Decision making by persons with life-limiting illness can be a complex process that includes but is not limited to decisions to continue aggressive care with or without palliative care, decisions to abandon aggressive care with or without palliative hospice care, and decisions regarding whom to communicate with and disclose their illness and prognosis (Campbell, Williams, & Orr, 2010; Wallace, 2015a). Throughout this process, family plays an integral role in making decisions about caregiving at EOL. Palliative

service providers, including hospice care providers, report that the care they provide is not just for the person with life-limiting illness but also for the family in that person's life (NHPCO, 2015a).

Persons with a life-limiting illness who have the capacity to make decisions are said to have individual autonomy (Blackler, 2016; Coyle, 2014). Making an autonomous decision at EOL could mean a person makes these decisions without any input or interference from family or friends. Coyle (2014) noted that many families might make healthcare decisions together as a cohesive unit. For persons with life-limiting illness who lack decision-making capacity, a surrogate or proxy is expected to make decisions that agree with what the person would have wanted at EOL. Surrogate decision making for the seriously ill has been reported to be very difficult from a psychological perspective (Dionne-Odom & Bakitas, 2012). Surrogates often are family members who may or may not have had advance direction regarding the person's EOLC needs or wants, which can change over time.

The literature is clear that care providers (e.g., interdisciplinary palliative teams) should guide and assist the seriously-ill person and their family when making decisions for EOL (Campbell et al., 2010; Cronin, Arnstein, & Flanagan, 2015; Radwany et al., 2009; Sullivan, da Rosa Silva, & Meeker, 2015). A common theme of communication as either a facilitator or barrier to families making these complex decisions emerged from the literature. Communication barriers that impacted FDM at EOL included lack of awareness of the person's serious illness and poor prognosis; family feeling unprepared or 'surprised' because of a lack of knowledge and then being rushed to make EOL decisions; non-English speaking families receiving less information; family feeling ill

informed about declining person's condition; families feeling rushed by the providers when recommendations for care were discussed; feeling their families' wishes are not being honored when family do not agree on the care suggested by providers; and families being aware of impending death but healthcare providers did not recognize this and continued aggressive care (Izumi & Van Son, 2016; Radwany et al., 2009; Sullivan et al., 2015).

Communication facilitators that impacted FDM at EOL found in the literature include families valuing communication with providers that included pertinent information regarding the seriously-ill person and using terminology they understood; emotional support for family by the providers; family understanding the seriousness of the person's condition and the poor prognosis; and when persons or their families could make choices about how they would communicate their EOL decisions to others (Campbell et al., 2010; Izumi & Van Son, 2016; Radwany et al., 2009; Sullivan et al., 2015).

Supporting and validating difficult and emotional decisions made by families at EOL when a loved one is dying, has found to be essential for building trust between the family and the healthcare team (Cronin et al., 2015). Families identified healthcare team interventions that created this trusting relationship when family decisions were made to transition the seriously-ill person to palliative care: nursing staff continuing to care for the person and their family; families were included in discussions regarding the process of their loved one dying; and providing a peaceful environment for the dying person and family. While being supportive with the family can facilitate FDM, there is little known about what factors affect certain cultural or ethnic groups making decisions at EOL.

Campbell et al. (2010) discovered through qualitative research several characteristics of African Americans' decisions at EOL. These characteristics included involving their provider; being guided by clinical factors; including family in most decisions about care; being influenced by religion and spirituality; using prayer to be closer to God; and appreciating the ability to choose how their illness and prognosis would be communicated to others.

Few publications were found that addressed FDM at EOL in rural Appalachia. Mixer et al.'s (2014) ethnonursing study about EOL care and family support in rural Appalachia revealed that families' reasons for choosing hospice care varied. The participants often needed help caring for the sick person and managing distressing symptoms as well as relief for caregiver exhaustion. In contrast, other participants declined hospice care, instead opting to continue curative care, possibly to avoid the stigma of death that accompanies initiating hospice care. In rural Appalachia, the person with a life-limiting illness and their family are seen as one unit. Several barriers are known to affect FDM about EOLC. Rural Appalachians tend to believe they are healthy until they are very ill and therefore often do not seek care until they have a life-limiting illness (Burkett et al., 2006). Family ties are strong and extended families typically live close to one another. When a member of the family is seriously ill, the immediate family will discuss future healthcare plans with the extended family before decisions are made (Burkett et al., 2006).

Ethics. While ethical problems at EOL can be related to the patient's main medical issue, they primarily are due to religious and cultural differences between the person and healthcare provider (Coyle, 2014). Because palliative and EOL care issues

are viewed through the Western societal lens in the U.S., EOL issues can be ethically challenging in an increasingly multicultural society. Ethical issues can arise from inadequate communication between the provider and family regarding EOL care and the inability of the person who is ill to make their own decisions (Coyle, 2014; Prince-Paul & Daly, 2015). Ethically, the goal is to respect patients, families, and their culture when caring for them at EOL.

Healthcare providers note that the leading cause of ethical concerns at EOL comes from disagreements between patients, family members, and providers regarding care (Pavlish, Brown-Saltzman, So, Heers, & Iorillo, 2015). This ethical challenge escalates when the healthcare organization does not promote and encourage early intervention by providers when there is disagreement involving shared decision making at EOL.

The culture of healthcare is changing and persons with life-limiting illness and their families are faced with more complex decisions than ever before. This in turn can create ethically difficult situations for the healthcare provider when assisting families in decision making, especially when the prognosis is uncertain. MacDonald, Weeks, and McInnis-Perry (2011) found in their grounded theory study that participants wanted to share with the healthcare team so they could understand that their loved one's life had meaning. The participants indicated there were key components that were essential when making family decisions. They included knowing the person's wishes and making decisions they felt were in their best interests; sharing stories about the person and the importance that extended family was part of the process to alleviate loneliness; using a process and voiced there was no one single decision; and feeling shocked and having

tension when these decisions had to be made quickly. The study goes on to describe how the participants felt the healthcare providers could be supportive of these families at EOL. Family members wanted clear communication, even if the healthcare provider felt it might be difficult to hear; healthcare providers to take the time to discuss their family member's prognosis so they would not make the family feel rushed to make decisions, and not to impose their personal opinions; the healthcare team to treat the dying person in a holistic way; and someone, such as an ethicist to bring all the elements of good communication together when making decisions at EOL. Family members want to be involved in the decision making at EOL. Being involved can increase their satisfaction with the process and prevent ethical issues that can occur when there is poor communication between the healthcare team and the family.

As previously mentioned, the principle of autonomy and the need for proxy or surrogate decision makers at EOL are critical. With all life-limiting illnesses, there generally will come a time when patients lack the cognitive capacity to make their own EOL decisions. The presence of a proxy or surrogate decision maker will require the interdisciplinary team to rely on the family or close friends of the person dying (Coyle, 2014; Prince-Paul & Daly, 2015). Surrogate decision making can create ethically challenging situations. One adult making decisions for another adult is based on the assumption that, as a family member or close friend, the surrogate will know the wishes of the person dying and have that person's best interests at heart. Surrogate decision making can be burdensome and stressful for the family. Within this stressful situation, Quinn et al. (2012) described informal roles family members may assume to make the best possible EOL decisions. These culturally defined roles demonstrate how the family

acts in stressful situations and must be considered by the healthcare team to avoid ethical challenges and facilitate the decision-making process. The roles are described below.

- The *primary caregiver* is the person who has spent the most time with the person who is dying.
- The *primary decision maker* usually emerges as the surrogate decision maker at EOL.
- The *family spokesperson* facilitates the decision-making process and communicates with the healthcare team when family members have questions or concerns.
- The *out-of-towner* is someone who had not been involved in the day-to-day care of the dying person and often has completely different opinions regarding the EOL decisions that have been made. For this reason, this person can create significant conflict among family members and the healthcare team.
- The *patient's wishes expert* helps the entire family come together to support the primary decision maker so the dying person's wishes will be met as closely as possible.
- The *protector* and *vulnerable family member* roles usually emerges when a child of the person dying steps up to protect an older parent from the stress of making decisions at EOL.
- The *healthcare expert* is a family member who influences decision making because of their supposed clinical expertise.

In summary, there is minimal literature about the ethical issues involved with FDM at EOL in rural Appalachia. However, the rural Appalachian family has been shown to make healthcare decisions together (Burkett et al., 2006). There also is a long history of rural Appalachians living day-to-day and handling acute health problems on the fly with little regard to the management of chronic health problems. Such practices can mean persons may present to a healthcare facility quite ill, having used folk medicine during some of or the entire illness trajectory (Hufford, 2006). From the literature, we know families wish to integrate their generic (folk) care with professional care at EOL (Mixer et al., 2014). To avoid ethical conflicts, Western traditions must be put aside while the cultural needs of these persons are considered by interdisciplinary teams prior to communicating with families regarding EOL treatment options.

Spirituality. Recognizing the spiritual needs of persons and their families when EOL decision making occurs is of fundamental importance (Baird, 2015). Family decision making at EOL is challenging by not only the family but also by the interdisciplinary team who must support family members as well as consider treatment and care goals (Kirchhoff & Faas, 2007). With prognosis changes and worsening conditions, families are not only facing the fact that their loved one may die but, because of likely cognitive impairment, also that they may be responsible for making or contributing to care decisions. There also can be a struggle to maintain hope during this difficult time, which can affect the entire family as they make decisions for their loved one. It is critical to provide cultural and spiritual support for the family members who are making decisions, as cultural differences will direct preferences regarding EOL care.

Spirituality is an elusive concept and that may be expressed only in terms of religion, as these terms sometimes are used interchangeably (Baird, 2015). Some EOL literature has described spirituality within the context of family as connectedness or being connected to family as one of the most important things in their lives (Dose, Leonard, Peden McAlpine, & Kreitzer, 2014). Other qualitative research revealed that spirituality can take the form of prayer for their families as a part of their spiritual journey to make peace with dying (Bell Meisenhelder, D'Ambra, & Jabaley, 2016). Decision making in the African American community at EOL is reported to be influenced by religion and spirituality (Campbell et al., 2010). One participants in this qualitative study said "The Lord, yeah, the good Lord. I'm putting it in His hands... He can cure it, you know, more than the doctors know, so I'm not going to give up the faith" (p. 220).

Chapter Summary

In summary, there is scarcity of research on the topic of FDM at EOL in rural Appalachia. Geographically isolated and medically underserved, rural Appalachians also have less access to EOLC (Daly & Matzel, 2013; IOM, 2015c; USDHHS, 2016a; Appalachian Rural Commission, 2016). The literature about rural Appalachian persons' ethnohistory and worldview reveals that there is a strong and complex connection between these people and their community networks and close family ties are vital to EOLC (Gotts & Purnell, 1986). Rural Appalachian people often consult healthcare professionals only as a last resort when symptoms have become severe and/or an illness has become acute (Behringer & Krishman, 2011; Coyne, 2006). They also may have scarce management of chronic health conditions due to the fatalism that comes from their cultural beliefs (Behringer & Krishman, 2011; Coyne, 2006). Fatalism in rural

Appalachia often has meant that persons felt life-limiting illness was the will of God. The anecdotal literature reveals that rural Appalachians make decisions at EOL for their family members while often reaching out to extended family for advice (Drogan, 2006).

While the literature is scarce, Mixer's et al. (2014) qualitative research results revealed that family support is important at EOL in rural Appalachia and that hospice care was chosen because the family needed assistance to physically care for and control the dying person's symptoms. Campbell et al. (2010) found that trust between the family and the healthcare team was imperative for effectively transitioning the patient to palliative care. The overarching theme found throughout the anecdotal and scarce research literature was that strong family and community ties and faith in God as the ultimate healer provide the main support for rural Appalachians during illness and death.

This literature review contributes to what is known about the ethnohistory and cultural needs of rural Appalachian persons. It also has offered insight to what is not known about this diverse population when life-limiting illness is present and decision making occurs at EOL. No current research was found that explored culture care expressions, patterns, and practices that influence rural Appalachian families when decision making at EOL. Discovery of the cultural support necessary for such families' will build on the minimal scholarly work available and uncover knowledge that nurses can use to provide culturally congruent care for this population.

Chapter Three: Methodology

The ethnonursing method is congruent with the purpose of this study to discover the expressions, patterns, and practices related to FDM at EOL among the rural Appalachians of eastern Tennessee (Wehbe-Alamah & McFarland, 2015a). For most people who live among the beautiful, rolling, and tree-capped mountains of the eastern Tennessee region of rural Appalachia, lifeways and healthcare traditions have continued with little change over the past 50 years. Minimal literature has been published to document FDM at EOL within the rural Appalachian culture. This chapter will discuss the ethnonursing research methodology, data collection and analysis processes, ethical considerations, and the rigor of the methodology.

Ethnonursing Research Method

The ethnonursing research method is a naturalistic and open discovery method that was designed to be used with Theory of Culture Care Diversity and Universality (Wehbe-Alamah & McFarland, 2015a). This method was well suited for facilitating the discovery of both emic (generic/folk) and etic (professional) perspectives related to rural Appalachian persons' cultural beliefs and lifeways during FDM at EOL. This method enabled the researcher to respectfully enter the world of the rural Appalachian family EOLC decision makers and gain knowledge about their largely unknown and complex emic expressions, patterns, and practices at EOL (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a). Discoveries from this cultural group will facilitate the provision of culturally congruent nursing and interdisciplinary care for this unique population group.

Research Enablers

Research enablers were used by the ethnonursing researcher to retrieve complex data and provided a relaxed and natural way for the informants to share their experiences (Wehbe-Alamah & McFarland, 2015a). The Sunrise Enabler, Stranger-to-Trusted-Friend Enabler, and the Observation-Participation-Reflection Enabler were used to “examine the major tenets of the theory” within the context of this study’s domain of inquiry (Leininger, 2006a, p. 24).

Sunrise Enabler. The Sunrise Enabler (Appendix B) provided a cognitive map of the CCT that guided the researcher in discovering factors that influenced rural Appalachian FDM at EOL. The researcher used the enabler to examine systematically rural Appalachian worldviews, cultural and social structure dimensions, and generic (folk) and professional care practices. The data collected was used to formulate culturally congruent decision and action recommendations that healthcare providers can use to contribute to families’ health, well-being, and the dying process (Wehbe-Alamah & McFarland, 2015b).

Stranger-to-Trusted-Friend Enabler. Through self-assessment, The Stranger-to-Trusted-Friend Enabler (Appendix C) guided the researcher to a more conscious awareness of the informants’ feelings and responses during data collection (Wehbe-Alamah & McFarland, 2015b). The researcher spent a great deal of time with rural Appalachian informants. To solicit authentic and credible data, the researcher established a therapeutic and trusting relationship so family members felt they could freely express themselves, sharing their inner most values, beliefs, and practices.

Observation-Participation-Reflection Enabler. The Observation-Participation-Reflection (OPR) Enabler (Appendix D) was used as a guide for observing and obtaining observations from both key and general informants (Wehbe-Alamah & McFarland, 2015b). The researcher moved through four stages of engagement with families to obtain accurate data and a full understanding of the domain of inquiry. Initially, the researcher remained in the role of observer and active listener to begin understanding the EOL context. In the next stage, the researcher moved into deeper observation with limited participation and then adopted a more active role within the rural Appalachian families' environment. Finally, the researcher engaged in a time of reflection giving her and the family time to confirm the data.

Data Collection

Data was collected within a 40-county area of eastern Tennessee (Figure 2, Appendix A), designated part of rural Appalachia by the Appalachian Regional Commission (2016). The researcher has lived and worked in rural Appalachia for more than 53 years and engaged with key gatekeepers to gain access to potential research participants.

Participants

The philosophic and epistemological sources of knowledge using the ethnonursing research method are "the people as the knowers about human care and other nursing knowledge" (Leininger, 2006a, p. 52). For this study, participants are referred to as informants. Key informants were people who held the most knowledge for answering the research questions. General informants provided views of a wider population and important reflective data that further facilitated the researchers'

understanding of person's meanings and experiences. The number of participants recommended for ethnonursing research varies depending on whether the study is considered a mini- or maxi-level investigation. Data saturation was obtained, with 10 key and 15 general informants, making this a maxi-ethnonursing study (Wehbe-Alamah & McFarland, 2015a).

Key informants were adults 40 years or older with a life-limiting illness who have months, weeks, days, or hours to live and/or their adult family members (18 years of age or older). Informants were born and raised in rural Appalachia and were willing to share their views on FDM at EOL. The 40-county area (Figure 2, Appendix A) has a population that is 93% white (non-Hispanic), and all informants spoke English (U.S. Census Bureau, 2015a). General informants were healthcare providers over age 25 who were routinely involved with the study population. For example, general informants were EOL, palliative, and acute care professional care providers and members of the interdisciplinary team.

Informant Recruitment

To recruit informants, the researcher contacted potential general informants within the east Tennessee region of rural Appalachia either in person or via phone or email. Key/general informant recruitment communications are included in Appendices E1 and E2. Using the Snowballing technique, general informants served as gatekeepers for key informants. Key/general informant flyers (Appendices F1 and F2) were used by the general informants to provide research study and PI contact information to potential informants. General informants forwarded potential key informant names and contact information (at informant request) to the PI. The researcher contacted and consented all

key and general informants. Potential recruitment problems could have included difficulty identifying potential informants and study attrition due to death or dropout; however, none of these recruitment challenges were experienced. Through her years as an acute care nurse practitioner in the area, the researcher has established trusting relationships with the necessary gatekeepers, which was invaluable for recruitment.

Data collection consisted of observations and individual interviews with informants after informed consent was obtained (Appendices G1 and G2). Observations before and during the interviews about the environmental context, artifacts, nonverbal informant expressions, interview time and location, and researcher thoughts, feelings, and hunches were recorded in a field journal. Information collected was digitally audiotaped, transcribed verbatim, and de-identified thru coding. Interviews lasted 30–60 minutes. One to two interviews were conducted per informant and these occurred either in-person or via telephone. NVivo™ qualitative software package was used to store and analyze data.

Ethical Considerations

The goal of this ethnonursing research study was to discover the culture care expressions, patterns, and practices of rural Appalachian persons making decisions at EOL, in order to produce information that could be used to improve care for patients and their family caregivers. EOLC studies are challenging for several reasons: death is a sensitive subject, dying persons and their families are considered vulnerable populations, and the methodology uncovers deeply personal expressions, patterns, and practices at EOL that must be handled sensitively to prevent participant burnout (Ferrell, Grant, & Sun, 2015; Henry & Scales, 2012; Kavanaugh & Campbell, 2014). The

researcher is an expert nurse, practitioner, and educator in EOL and EOLC and was sensitive to all informants' concerns.

Institutional Review Board (IRB) (Appendix H) approval was obtained from the University of Tennessee, Knoxville (UTK) prior to beginning this study. Permission to accept UTK IRB approval was provided by the acute care facility from which many informants were recruited (Appendix I).

Potential risks of participating in this ethnonursing research study included emotional distress due to the sensitive nature of the questions that were asked during the interview and informant fatigue and subsequent burden related to lengthy interviews. The study was introduced to gatekeepers, including any interdisciplinary team members that were asked to participate as general informants (as described above). Clear, broad, inclusion criteria were set in order to maximize informant recruitment. Interview questions (Appendices J1 and J2) used sensitive language that communicated with the rural Appalachian informants in a way they easily understood. Interview appointments were made at times convenient for informants, with flexibility to reschedule or stop the interview at any time to accommodate possible informant fatigue. A loss of confidentiality also was a potential risk related to this research. It was possible informants could be linked to their data or their association with the study. Even when safeguards were used to minimize the likelihood of an unintentional disclosure, such a disclosure was still a risk associated with the study.

It is well documented that repeated exposure to environments where there is the constant need to help someone who is suffering and dying leads to difficulty in providing services to this patient population and eventual burnout (Abendroth & Flannery, 2006;

Santiago & Abdool, 2011; Vanderspank-Wright, Fothergill-Bourbonnais, Malone-Tucker, & Silvar, 2011; Wiegand & Funk, 2012). Since the researcher was the primary data collector, self-care strategies were put in place to mitigate this type of stress. Strategies included journaling, exercising, peer and mentor support, and limiting the number of interviews conducted in any given period. These strategies enabled the researcher to be present as an open, active listener, who could express empathy and caring (Kavanaugh & Campbell, 2014).

Data Analysis

The data used in this research study came from interviews and field data gathered from key informants (rural Appalachians involved in FDM at EOL) and general informants (healthcare providers caring for patients and families at EOL). The research questions were used to explore the culture care expressions, patterns, and practices that influence rural Appalachian decision making at EOL.

Qualitative Ethnonursing Data Analysis Method

Data was systematically analyzed using the four phases of ethnonursing data analysis (Appendix K) (Wehbe-Alamah & McFarland, 2015b). These phases incorporated methodological rigor and guided the researcher to discover the culture care expressions, patterns, and practices embedded within field notes, observations, and interview data collected.

During phase one, the researcher began to immerse herself into the rural Appalachian community where informants were recruited. The researcher observed community members and recorded data pertinent to this ethnonursing study's domain of inquiry from both an emic (person) and etic (professional) perspective. Once consent

was given, the researcher began to collect key and general informant raw data through open-ended interviews. The data was transcribed by a professional transcriptionist, and entered into NVivo™ qualitative computer software program. The Leininger-Templin-Thompson-Ethnoscript Coding Enabler (Appendix L), which incorporates CCT domains, guided the coding structure for data analysis (Wehbe-Alamah & McFarland, 2015b). Data analysis began the initial day of research and continued throughout the study.

Phase two involved studying the data for similarities and differences from emic and etic perspectives, and refining coding (Wehbe-Alamah & McFarland, 2015b). Patterns were explored and identified, and meanings were analyzed.

Phase three involved examining data for saturation and recurrent patterns regarding the meanings-in-context of the rural Appalachian EOL FDM (Wehbe-Alamah & McFarland, 2015b). Phase four involved the researcher synthesizing and interpreting data patterns to create major themes. Findings were confirmed with key and general informants via email contact. These informants confirmed the accuracy of the researcher's findings. Recommendations were made for culturally congruent nursing/interdisciplinary team actions to support families making decisions at EOL (Wehbe-Alamah & McFarland, 2015b). Throughout all data analysis phases, the researcher applied the ethnonursing criteria for qualitative study rigor.

Evaluation Criteria for Ethnonursing Research Findings

Qualitative rigor using the ethnonursing research method was necessary to substantiate and discover credible expressions, patterns, and practices of rural Appalachian families that must make decisions at EOL. To promote rigor, Leininger (1997, 2006b) developed five criteria when using the ethnonursing method: credibility,

confirmability, meaning-in-context, recurrent patterning, saturation, and transferability. Leininger (2006b) discussed the value of mentoring when using the ethnonursing research method to help the researcher reduce bias and prejudices, reflect on the data, satisfy rigor, analyze large amounts of qualitative data, make cultural connections among the diverse and universal findings, and publish ethnonursing research findings.

Credibility. Credibility is the “truth, accuracy, and believability of findings” (Leininger, 1997, p. 56; Wehbe-Alamah & McFarland, 2015a). When conducting interviews with key and general informants, the researcher mutually clarified and documented meanings, situations, and events. Direct experiences with rural Appalachian families over time created trustworthiness as well as meanings-in-context that supported the credibility the study’s findings.

Confirmability. Confirmability refers to “repeated direct and documented objective and subjective data confirmed with the informant” (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a, p. 57). Some informants were contacted via email and asked to review and reaffirm what the researcher saw, heard, or experienced. Informants confirmed findings related to themes and patterns, providing valuable feedback about the accuracy of the researchers’ discoveries. An audit trail was created to document how the researcher moved from raw data to patterns and themes. The researcher created notes and memos in NVivo™ to help clarify her thoughts during data analysis. The study mentor listened to the audio interviews, and examined the field notes and memos to confirm what the researcher had heard, recorded, and analyzed and that the data reflected the emic perspective.

Meaning-in-Context. Meanings-in-context refers to “findings that are understandable to the informants studied within their natural and familiar environment” (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a, p. 57). This criterion focuses on the researcher’s ability to understand the actions, experiences, communications, or observations from the emic perspective. This criterion was met by spending time with informants, keeping detailed field notes, and creating notes when analyzing data to confirm the researcher understood the meaning of data collected within the cultural context of rural Appalachian families.

Recurrent Patterning. Recurrent patterning refers to “repeated instances, patterns of expressions, sequences of events, experiences, or lifeways that tend to occur over a period of time in designated ways or contexts” (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a, p. 57). The researcher spent extensive time in the study environment and collected data from 25 informants to ensure that findings reflected authentic, repeated, culture care expressions, patterns, and practices of rural Appalachian FDM at EOL.

Saturation. Saturation refers to “the exhaustive search from informants of data relevant to the domain of inquiry in which no new findings are forthcoming...” (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a, p. 57). When the researcher heard data repetition and no new findings were discovered, saturation was met and data collection ended.

Transferability. Transferability refers to “whether particular findings from a qualitative study can be transferred to another similar context or situation” (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a, p. 58). The researcher anticipates that

nurses and other healthcare professionals caring for similar and diverse cultural groups could use these study findings as they assist families making decisions at EOL.

Chapter Summary

The goal of using the ethnonursing research method was to discover the culture care expressions, patterns, and practices of rural Appalachian families making decisions at EOL. The ethnonursing research enablers assisted the researcher assimilate into the field, promoted guided reflection, and lead to authentic, rigorous, and credible findings.

Chapter Four: Findings

This ethnonursing study describes the EOL decision-making culture care expressions, patterns, and practices of rural Appalachian persons and families. In this study's context, families included the person with a life-limiting illness and the people deemed significant in their lives. Ethnodemographics and ethnohistory discovered during the study are described. Four universal themes are supported by universal and diverse patterns. Salient key and general informant quotes illustrate the rural Appalachian worldview and cultural and social structure dimensions within the context of EOLC. Culture care decision and action modes that promote culturally congruent care when making decisions at EOL are presented.

Ethnodemographics

Informants (n=25) in this study were obtained from the East Tennessee region of rural Appalachia identified as the informant recruitment area. Because the region has small communities where many people know one another, minimal demographic information is reported in an effort to maintain informant confidentiality. Key informants (n=10) were males (n=3) and females (n=7), with a mean age of 47.9 years of age, who self-identified as rural Appalachian, and were willing to share their experiences of FDM at EOL. All key informants reported graduating from high school, and five had a college degree. Four key informants were family members with a loved one (spouse or parent) who had already died when their interview took place. Six key informants had a parent hospitalized in an acute care setting with a life-limiting illness and were actively making EOLC decisions.

General informants (n=15) were males (n=3) and females (n=12), with a mean age of 47.9 years of age. These persons included registered nurses (n=6), healthcare providers (HCP) (n=6), a social worker (n=1), and case managers (n=2). Their mean number of years within their current role was 13.5 years. Education level ranged from an associate degree in nursing (n=4), bachelor of science in nursing (n=4), master of science in nursing (n=4), physician assistant degree (n=1), master of social work (n=1), and a doctor of medicine degree (1). Ethnic heritage was self-identified as white rural Appalachians (n=7), white American (n=6), and black American (n=2). All general informants were engaged with and cared for the rural Appalachian person and their family as they made decisions at EOL.

All informants spoke English as their first language. Each key and general informant self-identified as Christian. Interviews were conducted in a place chosen by the informant. Key informants were interviewed in their home, the family member's hospital room, or in another place of their choosing. General informant interviews took place in a private location in the work setting such as an office or conference room on the unit.

Ethnohistory

The rural Appalachian worldview, culture and social structure dimensions, environmental context, language, and ethnohistory are described below within the context of person and FDM at EOL. These descriptions emerged from interview data and the researcher's observations and field notes.

Worldview

The worldview of rural Appalachians interviewed for this ethnonursing study was clearly shaped within the context of caring for and being loyal to family. These informants conveyed a strong and complex kinship that was expressed in their day-to-day living, especially when a family member was faced with a life-limiting illness that required EOLC decisions. Key informants were mostly very traditional rural Appalachian persons. Two informants had out-migrated from their community to another state. All other key informants lived in small communities close to the family member with a life-limiting illness. The regional hospital where many of the interviews took place is the closest multi-discipline acute care facility for key informants and their family to receive care. The acute care facility does not offer a formal palliative care program or formally trained palliative care providers. Additionally, there are no home palliative care programs in the region. However, the acute care facility does provide comfort care and hospice care is available within the region.

Cultural and Social Structure Dimensions

The CCT social and structural dimensions include kinship and social factors, economic and education factors, religious and philosophical factors, and language and communication factors. These factors are described in the literature as being influential to the rural Appalachian's day-to-day existence and also were found to affect this study's key and general informants when decision making at EOL.

Kinship and social factors. Key informants expressed that while everyone knew their loved one was seriously ill, each person and family had to traverse the illness trajectory. At the time of the interview, six key informants identified themselves as family

members who were sitting and being with a dying person. Gatekeepers formally introduced the researcher to key informants. The researcher always tried to establish relationships with informants so they felt comfortable answering questions.

All informants honored their elders and expressed the desire to carry out their wishes if possible. The researcher also noted multigenerational relationships with grandchildren staying with their dying family members at the acute care facility. Family cohesiveness was seen as vital for decision making, with most key informants expressing the need to be with the dying person and the importance of everyone being “on the same page.” General informants stated it was common for there to be “a roomful” of multigenerational persons when someone was dying. The researcher observed love expressed among members of the rural Appalachian community. Many informants spoke openly of how much assistance they received—in the form of food, prayer, and transportation—from friends, church members, and even work colleagues.

Most key informants continued to live in the small communities their families called “home.” Out-migration was discussed by two key informants, which they felt created a delay in accepting the family member’s life-limiting illness. For example, an aunt was serving as the primary family caregiver. Adult children from out of town visited during a hospitalization and despite the aunt’s desire to continue aggressive care, interdisciplinary team members informed them that their father was ready for hospice. In fact, their father was transferred to inpatient hospice and died within two days. General informants confirmed this was common when extended family members out-migrated from the community and came home to find the illness more progressed than expected. This challenge certainly influenced EOLC decision making by the person or family.

Economic and educational factors. Economic concerns influenced key informants when making decisions at EOL. Eight of the ten key informants lived in rural areas, and two of these were part of a rural Appalachian agricultural family. Five of the key informant women reported working outside the home to supplement the family income. One key informant's spouse left the family farm and began his own logging company to meet financial obligations. For some families, economic challenges were thrust upon them during the family member's illness. For others, pre-planning allowed economic hardships to be avoided. In either example, all general informants reported economics as a major factor affecting FDM for EOLC in this rural Appalachian region, mostly related to the fear of economic hardships.

Formal education is valued in this rural Appalachian region. All informants had graduated from high school, and all general and five key informants reporting some college education. Even with mandated formal education, key and general informants exhibited limited EOLC and illness trajectory knowledge and had unrealistic care expectations.

Religious/spiritual factors. All key and general informants expressed their faith during their interviews. Having a minister was identified as a general or folk care practice that gave comfort at a difficult time. Baptizing the dying person also was reported as a faith practice by key and general informants, as it was seen as essential for the dying person's afterlife. Informants reported it was not unusual to use the physical therapy's department whirlpool to baptize the person whose death was imminent. Some key informants revealed that the church family was essential in

comforting both the person dying and their family and that this same faith comfort was essential in their folk and professional care.

Healthcare Expressions, Patterns, and Practices

Informants' limited medical knowledge led to a lack of understanding about EOLC options. For example, one key informant reported that her aged father had been "passing blood" with bowel movements but had not revealed this until he was quite ill. He was subsequently hospitalized and diagnosed with metastatic colon cancer. This informant's father only lived five weeks following his diagnosis and spent only seven days in hospice care. Interestingly, only two of the 10 key informants reported their loved one had an advanced directive.

Themes of Rural Appalachian Family Decision Making at End of Life

Rural Appalachian key informants and rural/non-rural Appalachian general informant's data were analyzed from interviews, informant experiences, field notes, and journal observations. Four major themes were derived from the expressions, patterns, and practices of FDM at EOL. The following four themes were supported by recurrent care patterns and key and general informant descriptors:

- Theme 1 – Rural Appalachians make EOL decisions with family;
- Theme 2 – Communication encompassing EOL FDM is essential and complex;
- Theme 3 – Education and economics influence FDM at EOL; and
- Theme 4 – The need for comfort for living while dying.

Major study findings—themes, patterns, and informant quotes—are presented in Tables 1–4 in Appendix A.

Theme 1 – Rural Appalachians Make EOL Decisions with Family

Key and general informants shared many common responses. As family members navigated the illness trajectory (diagnosis to death), each described a journey toward accepting death as part of life. Additionally, rural Appalachian families described that having faith in an afterlife influenced their EOL decision making. The following three recurrent patterns support theme 1:

- Pattern 1 – Rural Appalachian families' awareness of the illness trajectory (diagnosis to death) moves at different rates, which influences EOL decision making;
- Pattern 2 – Accepting death as a part of life influences rural Appalachian family decision making at EOL; and
- Pattern 3 – Faith influences EOL family decision making.

Recurrent care pattern 1 (rural Appalachian families' awareness of the illness trajectory [diagnosis to death] moves at different rates, which influences EOL decision making) was discussed by key informants universally (salient quotes in Table 1, Appendix A). While many key informants said they knew their family member had life-limiting illness, they continued to hope this was not the case as they traversed the illness trajectory. This care pattern also was confirmed by general informants, many of whom noted that family members traverse illness trajectory at different speeds. Informants saw many ill persons being admitted to the acute care facility who had families with unrealistic expectations about their care. Many family members felt that "a pill" should fix most things, a belief that complicated FDM.

The second theme one recurrent care pattern was that accepting death as a part of life influences rural Appalachian FDM at EOL (salient quotes in Table 1, Appendix A).

Even when the family knows death is coming, they still hope it is not. Key informants revealed that families' acceptance of death occurred over time. For example, one key informant said that the family delayed making a decision about a hospice referral because no one thought dad would live only five weeks. While some families reported wanting to stop palliative treatment, the ill family member wanted to continue. In contrast, other key informants expressed their complete acceptance of death and reported being "ready to go." General informants confirmed this pattern, describing how difficult it was to determine the best way to assist families in accepting the inevitable progression of the life-limiting illness, which required them to make EOLC plans.

The third universal care pattern for theme one was that faith influences EOL FDM (salient quotes in Table 1, Appendix A). All key and general informants expressed faith in their "Lord" and in an "afterlife," which made decision-making for EOLC less of a struggle. General informants also confirmed that strong faith seemed to help family members be more "settled about the next step in life" and accepting that making EOLC decisions was necessary. Two key informants spoke of prayer as it informed their faith in "the Lord" and created comfort regarding their decisions for their father's EOLC. Five general informants said prayer was a vital part of their interdisciplinary practice and that they have witnessed prayer many times with persons and their families at EOL.

Theme 2 – Communication Encompassing EOL Family Decision Making is Essential and Complex

Key and general informants recognized that while the communication among the person with the life-limiting illness, their family, and interdisciplinary team members is complex, it also is essential. Informants asserted that sharing information and hearing

one another was necessary to facilitate productive FDM at EOL. This theme is advanced by three universal care patterns:

- Pattern 1 – Rural Appalachians describe that EOL family decision-making communication is a burden on someone (family and interdisciplinary team);
- Pattern 2 – Interdisciplinary team members plant seeds for families to consider when making decisions at EOL; and
- Pattern 3 – The concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members.

Theme two's first recurrent care pattern (rural Appalachians describe that EOL FDM communication is a burden on someone [family and interdisciplinary team]) reflected the fact that someone has to begin the communication process (salient quotes in Table 2, Appendix A). One key informant said that the decision to stop her spouse's palliative treatment was made only after her family members explained the “medical stuff.” In general, key informants stated that having advanced directives facilitated communication about EOL decisions. Key informants also reported that having a person who knows the dying person's wishes, with or without an advanced directive, facilitated FDM at EOL.

General informants confirmed this universal communication pattern by revealing how important it was to involve family early on in the decision-making process by explaining it “to them early on and in terms they could understand.” General informants also confirmed the importance of providing continual support to the family members who made EOL decisions. Informants described how family members struggled with

wondering if they made the “best decision they could” and abided by the dying patient’s wishes.

The second care pattern for theme two was that interdisciplinary team members plant seeds for families to consider when making decisions at EOL. Effective communication between family members and the interdisciplinary team is essential if families are to have the information needed to facilitate well-informed decisions for their loved ones at EOL (salient quotes in Table 2, Appendix A). Both key and general informants discussed how poor prognostication of death inhibited effective family EOL decision making. One daughter said, “I could not get any doctor or anybody at the hospital to give me an idea of how long he might have.” Key informants expressed that, without a death prognosis, many family members would maintain a “sliver of hope [for] recovery,” making palliative or hospice referrals difficult. General informants confirmed that not being able to provide the family with a close approximation of time of death sometimes creates a feeling of hope that the illness is not life limiting. Some family members may believe that with faith there still may be “a miracle,” so they continue aggressive care instead of transitioning to EOLC. General informants expressed that while it was impossible to give family a definite time of death, many providers sent mixed messages by continuing aggressive care, and then suddenly saying it was time to transition to EOLC. Often such communication came very close to death, making EOLC decisions difficult. Key informants revealed that many providers effectively communicated the illness stage to the family. Many general informants reported that some interdisciplinary team members were better at this essential communication than were others.

The third care pattern was the concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members. Productive FDM about EOLC requires direct communication among the dying person, their family, and interdisciplinary team members. Such open, truthful discussions led to mutual decisions that reflected the person’s wishes for EOLC. One key informant said she constantly requested that interdisciplinary team members communicate information to her father and other family members “because I’m having to process all of this” as well. One barrier to this type of communication was families and in some cases interdisciplinary team members not understanding EOLC options. Analysis of field notes and interview data revealed there often was no distinction between palliative, hospice, or EOLC. Therefore, even when the burden to communicate fell on someone, and the “seed was planted” regarding EOLC decision making, it was difficult to “lay it on the line” if the family does not know about or understand all the care options.

Theme 3 – Education and Economics Influence Person and Family Decision

Making at EOL

Key and general informants noted that rural Appalachian families generally lack palliative care knowledge and family economic support and that these deficiencies created barriers to EOLC FDM. The following two universal recurrent care patterns support theme 3:

- Pattern 1 – Rural Appalachian EOL family decision making is influenced by a lack of knowledge about the illness trajectory (diagnosis to death) and EOLC; and

- Pattern 2 – Rural Appalachian family decision making at EOL is influenced by economics, the need to choose “the lesser of two evils.”

The first care pattern for theme three was that rural Appalachian EOL FDM is influenced by a lack of knowledge about the illness trajectory (diagnosis to death) and EOLC (salient quotes in Table 3, Appendix A). Key informants richly described their lack of understanding about illness trajectory and the need for “constant reinforcement” from the interdisciplinary team that their decision making was appropriate. Additionally, key informants were quick to say that, even though their dying loved was not educated much past the elementary school level, they still considered them “educated.” General informants confirmed that education-appropriate language was important when speaking to families. They also reported the need to educate family about care expectations and palliative care options. These care actions were viewed as facilitators to FDM at EOL. While some general informants spoke about differences in families’ understanding of illness trajectories and care options, several interdisciplinary team members also described limited knowledge of the differences in EOLC options such as palliative and hospice care.

Pattern two for theme three is that rural Appalachian FDM at EOL is influenced by economics, the need to choose “the lesser of two evils” (salient quotes in Table 3, Appendix A). Universally, whether it was the lack or presence of economic support in the home, EOLC was influenced by financial resources. For key informants with abundant resources, EOLC decisions were facilitated by the freedom from worries about losing their family member’s home or depleting their funds. Others however reported the lack of financial resources as a barrier to EOLC decision making. For

example, one working family member described the “hardships” that would occur if she quit her job to be home with the dying family member. General informants discussed their concerns about sending someone home with “hospice” care and then no one being home with the person because the family had to work. General informants also reported a “fear” of families putting “their home in jeopardy” in order to afford care at a skilled nursing facility and were concerned about where a spouse would reside after their loved one died. General informants also spoke about aggressive treatment that cost more than the family could afford.

Theme 4 – Comfort: Living While Dying

Key and general informants revealed that supportive care for families’ decision making at EOL included folk or generic care that created a “sense of normalcy” when living with a life-limiting illness. The following universal and diverse care patterns support theme four:

- Universal pattern – Folk (emic) care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy;” and
- Diverse pattern – Some rural Appalachian families felt hospice care was helpful and some did not.

The universal pattern for theme four is that folk (emic) care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy.” Food and faith were discovered as folk care, that helped families dealing with life-limiting illness and facilitated decisions for EOLC (salient quotes in Table 4, Appendix A). Key informants noted that their usual daily activities before their loved one became ill—gardening, farming, driving, and spending time with other friends and family—became

supportive folk care practices while their loved one was dying. General informants confirmed this finding of promoting normality when possible by describing rural Appalachian families' use of herbal medicine. One general informant stated that folk remedies often were "handed on down" among the family. In fact, families frequently tried folk care first to avoid "insulting their older people or their heritage." Another general informant believed that the use of folk remedies often resulted in a delay in seeking care, as they felt they can "fix things at home." When this occurs, patients often present to a healthcare facility when they are very ill.

The diverse pattern for theme four was that some rural Appalachian families felt hospice care helpful and some did not. One key informant revealed how helpful hospice care had been for her dad and family, stating she could not "imagine having to go through [her dad dying] without them..." However, the daughter also described how "my mom still thinks that hospice killed him." Even though families valued hospice care, they only used such services at the very EOL. For example, one informant stated, "... though hospice was wonderful... we may have only had the hospice care for about a week and half." General informants confirmed these findings describing diversity in how hospice is perceived by families at EOL. Most families who have accepted a hospice referral describe a positive experience. However, general informants discussed the negative "reputation" of hospice as well as the difficulty of referring families to hospice once the word "hospice" was used by the interdisciplinary team. The most striking belief noted during a discussion with a general informant was how families felt a hospice referral meant "you're just gonna let 'em die now."

In summary, rural Appalachians make EOL decisions with their families while engaging in essential and complex communication with family and interdisciplinary team members. Family decision making at EOL is influenced by education and economics factors and these families value a continued sense of normalcy and living while their loved one is dying.

Nursing/Interdisciplinary Team Decisions and Actions

This study described universalities and diversities among rural Appalachian families making decisions at EOL. Within the context of the CCT and ethnonursing method, these findings were used by the researcher to recommend nursing/interdisciplinary decisions and actions that support the rural Appalachian care expressions, patterns, and practices that contribute to culturally congruent FDM at EOL (McFarland & Wehbe-Alamah, 2015). The three CCT predicted modes are

- Culture care preservation and/or maintenance
- Culture care accommodation and/or negotiation
- Culture care repatterning and/or restructuring

Culture Care Preservation and/or Maintenance

Culture care preservation and/or maintenance includes professional acts or decisions that “help cultures to retain, preserve, or maintain beneficial care beliefs and values or to... face death” (McFarland & Wehbe-Alamah, 2015, p. 16). Nurses and other interdisciplinary team members are encouraged to adopt the following culture care preservation and/or maintenance actions (Table 5, Appendix A):

1. Respect rural Appalachian families as they move along the illness trajectory at different rates; and

2. Preserve generic/folk care that helps create a “sense of normalcy,” which provides support and comfort for living, even with life-limiting illness.

Culture Care Accommodation and/or Negotiation

Culture care accommodation and/or negotiation are professional actions or decisions that “help cultures adapt to or negotiate with others for culturally congruent safe and effective care for their health, well-being, or to deal with illness or dying” (McFarland & Wehbe-Alamah, 2015, p. 16). Nurses and other interdisciplinary team members are encouraged to adopt the following actions (Table 5, Appendix A):

1. Accommodate faith practices among rural Appalachian families when making decisions at EOL; and
2. Accommodate rural Appalachian economic diversity by assessing individual family resources, and developing a treatment and EOLC plan that fits the family’s cultural expressions, patterns, and practices; and
3. Accommodate rural Appalachian families’ diverse hospice perspectives by creating community partnerships to develop train-the-trainer programs in which trusted community members teach others about EOLC options.

Culture Care Repatterning and/or Restructuring

Culture care repatterning and/or restructuring are professional actions and mutual decisions that “help people to reorder, change, modify, or restructure their lifeways and institutions for better healthcare patterns, practices or outcomes” (McFarland & Wehbe-Alamah, 2015, p. 16). Nurses and other interdisciplinary team members are encouraged to adopt the actions detailed below (Table 5, Appendix A).

1. Repattern communication among families and interdisciplinary team members to facilitate family decision making at EOL by using easily-understood language and terminology, visual aids, and written materials that facilitate understanding of the life-limiting illness and EOLC choices.
 - An interdisciplinary team member must take responsibility to plant the seed by discussing the disease process and future EOLC needs with the family and interdisciplinary team members earlier in the illness trajectory.
 - All members of the Interdisciplinary team are responsible for constantly reinforcing treatment options, EOLC options, and disease progression.
 - Such communication strategies may help facilitate family decisions that reflect the dying person's wishes. Subjects for discussion include deciding which family members to include in discussions, designating a family member who will be responsible for giving information to other family members, and including distant family members using technology such as FaceTime, ZOOM, GoToMeeting, etc.
2. Develop culturally congruent palliative care education for interdisciplinary providers in acute care and community settings. General informants/ interdisciplinary team members had limited knowledge of the differences in palliative, hospice, and EOLC. Rural Appalachian families need to understand EOLC options in order to be able to make informed decisions.

Chapter Summary

This chapter presented the findings from this ethnonursing study. Informant demographics, rural Appalachian worldview, and ethnohistory with social structure dimensions discovered within the context of FDM at EOL were included. Major themes

and care patterns that supported these themes with salient quotes also were presented. CCT decision and action modes, developed from study findings, provide recommendations for nursing/interdisciplinary actions that support rural Appalachian families making decisions at EOL.

Chapter Five: Discussion

The purpose of this qualitative ethnonursing study was to discover and describe EOL family decision-making care expressions, patterns, and practices among rural Appalachians. Informants freely shared their expressions, patterns, and practices related to FDM at EOL, providing insight into culturally congruent generic and professional supportive and caring practices. Each of the five research questions that directed this ethnonursing study were investigated and answered. This chapter discusses how the CCT assumptive premises for this study were supported. Findings are compared and contrasted to other ethnonursing, FDM, and EOL studies. Implications for rural Appalachian families, EOLC clinicians, EOLC policy, and EOLC economics are discussed and future research recommendations suggested. Lastly, the researcher provides her personal reflections regarding rural Appalachians and FDM at EOL that may be helpful to those who choose to study other cultures.

Contribution to Nursing Theory

The CCT's theoretical assumptions guided this research study in the discovery of culture care expressions, patterns, and practices within the context of FDM at EOL in rural Appalachia. The following six of the CCT's 11 theoretical assumptions were adapted for this study and upheld by the findings (McFarland & Wehbe-Alamah, 2015).

Assumptive Premises

The first assumptive premise of the study—culture care is the essence of nursing care and the central, dominant, distinct, and unifying focus of EOL decision making for rural Appalachians and their families (McFarland & Wehbe-Alamah, 2015;,, adapted from assumption 1, p.8)—was supported by theme 4 (comfort: living while dying). Both

key and general informants recognized that rural Appalachian families who must make decisions for EOLC required care that was comforting. Key informants described caring actions of nurses and other members of the interdisciplinary team that helped them through this process.

The second, third, and fifth assumptive premises were supported by all four themes (see Chapter 4). The second assumptive premise is that culture care is essential for humanistic EOL decision making when rural Appalachians and their families face the transition from curative to palliative to EOL care (McFarland & Wehbe-Alamah, 2015; adapted from assumption 2, p.8). The third assumptive premise is that culture care expressions, patterns, and practices of rural Appalachian families' decision making at EOL are influenced by and embedded in their worldview, social structure factors (i.e., "religion, philosophy of life, kinship, politics, economics, education, and cultural values"; McFarland & Wehbe-Alamah, 2015, p.8) as well as the ethnohistorical and environmental context (McFarland & Wehbe-Alamah, 2015; adapted from assumption 6, p. 8). Key informants shared that EOLC decisions were made with family from within the rural Appalachian culture. Most accepted death as a part of living. Faith practices were strong in the face of life-limiting illness and influenced decisions about EOLC. Families described how important it was to have honest and frank communication about the EOLC wishes among family and interdisciplinary team members. Key informants described their own and the interdisciplinary team's lack of knowledge regarding EOLC choices and the need for culturally appropriate education in order to make decisions. Economic burdens limited EOLC options thus frustrating families as they made decisions. All families described culturally congruent EOLC as

having the freedom to live with a sense of “normalcy” while dying, as supported by folk and professional care.

The fifth assumptive premise was that Leininger’s three theoretical modes of care offer new, creative, and different therapeutic ways to help rural Appalachian families with decision making at EOL (McFarland & Wehbe-Alamah, 2015; adapted from assumption 9, p. 9) Table 5 in Appendix A provides recommended modes that support rural Appalachian families making EOLC decisions that are culturally congruent for them. The fourth assumptive premise—that the rural Appalachian culture of decision making at EOL has discoverable generic (emic) and professional care (etic) practices that can be used to provide culturally congruent support to these dying patients and their families (McFarland & Wehbe-Alamah, 2015; adapted from assumption 7, p. 9)—was supported by theme four. Rural Appalachians shared many generic care practices they felt were supportive when family made decisions at EOL, while general informants described the importance of folk remedies.

The sixth assumptive premise—that the CCT and ethnonursing method offer an effective way to discover largely embedded, covert, epistemic, and ontological culture care knowledge regarding decision making at EOL for rural Appalachians and their families (McFarland & Wehbe-Alamah, 2015, adapted from assumption 10, p. 9)—was supported by all study findings. Using the ethnonursing method made it possible for the researcher to enter into the world of rural Appalachia and uncover complex elements of FDM at EOL.

Care Constructs

Care constructs are cultural or symbolic meanings or knowledge of caring practices that are essential for providing culture-specific care (McFarland & Wehbe-Alamah, 2015). Thus far, 178 care constructs have been identified from more than 58 cultures through qualitative research using the ethnonursing research method. The following five care constructs describe the caring practices given to/by families who make decisions at EOL in rural Appalachia. The care constructs previously identified by ethnonursing researchers and discovered in this study were family involvement, communication, comfort, hope, and faith (McFarland & Wehbe-Alamah, 2015).

Family involvement. In the rural Appalachian culture, there were many examples of caring described as family involvement when decision making at EOL. Universally, families were involved in making EOLC decisions. However, familial relationships were sometimes described as complex yet essential. General informants also described decision making at EOL as a family event. While informants saw family as a facilitator to making decisions at EOL, informants also described barriers to decision making at EOL with family, especially when the wishes of the dying person were not known in advance. Embler (2012) studied the Yup'ik Eskimo cultural approach to EOL and found that the care construct of family involvement was essential when caring for the dying person, whether in community or acute care settings. Holt (2001) conducted an ethnonursing study about the EOL expectations of the Eritrea culture. She found family involvement within the culture as essential for comfort and support when there was a crisis.

Communication. Both key and general informants confirmed the care construct of *communication* as an essential and complex process when families make decisions at EOL. Communication among rural Appalachian families and interdisciplinary team members was found to be necessary for understanding the illness trajectory. Communication also was necessary for the interdisciplinary team to understand the dying person's wishes and for family to understand EOLC choices. Unique to this study, interdisciplinary team members were identified by key informants as responsible for initiating communication with family for discussion and reinforcement of the illness progression and future EOLC choices.

Although communication has been discovered as a care construct in this study, this researcher found no published ethnonursing studies describing communication as a care construct. However, conceptually, communication in the context of culture and dying has been reported using other qualitative methods. Using metasynthesis, Chi and Demiris (2017) examined family caregivers' experiences of pain management in EOLC. They found poor communication between family and interdisciplinary team members resulted in insufficient support for families and inadequate pain management. Khosla, Washington, Shaunfield, and Aslakson (2017) also found communication challenges within the cultural context of seriously-ill South Asian persons. Their qualitative thematic analysis found that multiple family members were present when someone was ill and identifying a spokesperson for communication posed a challenge. These South Asian families also displayed a passive communication style and a cultural norm of withholding medical information so the ill person was not upset. These studies demonstrate the diversity of communication challenges within different cultures, thus

supporting the need for culturally congruent communication care at EOL for all individuals regardless of culture.

Comfort. Informants universally described the care construct of comfort as living while dying with a feeling of “normalcy” within a family who is making decisions for EOLC. Folk and professional care were described as the usual activities of daily living of the person who is dying. Many described having friends and family close. Others discussed their faith in God as giving them comfort. Most key informants described how food was a part of their culture and provided comfort, especially if shared with family and friends. While Bonura et al. (2001) did not describe any care constructs discovered in their ethnonursing study; they identified that caring gives holistic comfort to their Jewish participants at EOL. Just as with rural Appalachian informants, Jewish informants described care as meeting their comfort needs in a physical, emotional, and spiritual way. Additionally, in an ethnonursing qualitative study, Gates (1988) discovered the theme of “living while dying” within the context of a hospital oncology unit and a freestanding hospice. Her findings reveal that nursing care can foster living even when dying, and facilitate an “appropriate or peaceful” (p. 178) death.

Hope. In the rural Appalachian culture, hope was universally described by key informants first as a hope that their loved one did not actually have a life-limiting illness, and second that they would not die. While key informants universally knew their family members were sick, they described holding out hope for healing when treatment plans were initiated, and some never “g[ave] up hope” of living. Generally, hope was described in the context of their faith in God. Some key informants described acceptance of death and hope in eternal life. Similarly, in their ethnonursing study in a

rural village in the Dominican Republic, Holt & Reeves (2001) described caring practices that nurtured hope. Even when times were bad, participants stated, “Hope is an essential but dynamic life force that grows out of faith in God, is supported by relationships, resources and work, and results in the energy necessary to work for a desired future. Hope gives meaning and happiness” (p. 128–129).

Faith. Faith (in others) has been previously described as a care construct (McFarland & Wehbe-Alamah, 2015). In this study, regardless of their self-identified religious affiliation, faith was differentiated by key and general informants as faith in “God” and faith in an “afterlife.” Informants also described how faith influenced EOLC decision making. In another ethnonursing study with rural Appalachians, Mixer et al. (2014) found that faith was “fundamental to rural Appalachians as they transitioned through EOL” (p. 530). Consistent with the findings of this study, informants described faith in “God,” faith practices such as bible reading and prayer, and “God’s” timing for healing and death. Surprisingly, in her ethnonursing study, Morris (2012) described the care construct of faith within the context of African American adolescents who were part of a gang. Adolescents described their faith in God had “gotten them through their times of sorrow and loss” (p. 266).

Professional Care Practice and Policy Implications

The goal of this ethnonursing research study was to discover emic (generic/folk) and etic (professional) care that supported rural Appalachian families to make decisions that will help them achieve culturally congruent EOLC. This study revealed that families are involved in EOLC decisions. As they understand the person has a life-limiting illness, families travel the illness trajectory, accepting death at different rates, while

some hold out hope that the person will not die. Through honoring families' faith, entering into partnership for culturally congruent communication, respecting persons' folk care, and providing comfort until death, nurses and interdisciplinary team members can support families in their decision making at EOL. Families also described challenges with their own and interdisciplinary team members' lack of knowledge about palliative and EOL care choices as well as the economics that influenced most choices.

Professional Care Practice Implications

This study has practice implications for nurses and interdisciplinary team members. In March of 2017, the American Nurses Association (ANA), in partnership with the Hospice and Palliative Nurses Association (HPNA), published a call to action that outlines steps and strategies for nurses to lead the way in palliative care (ANA, 2017). This document includes suggestions for palliative nurse education curriculum, the need for more palliative care content on pre-licensure exams, as well as funding of palliative care models to meet the needs of diverse and underserved populations and vulnerable groups. Families in rural Appalachia need to understand what their resources are in order to make meaningful choices for persons at EOL. NHPCO (2015a) reported that dying patients spent an average of seven or fewer days in hospice care. This study supports these NHPCO findings, as at least three of the four key informants had family with a hospice stay of seven or fewer days. These key informants also said they might have made different palliative care choices if they had achieved a better understanding of palliative care and the person's illness trajectory.

Some key and general informants reported that poor communication between families and the interdisciplinary team led to the provision of more aggressive care. This

is consistent with findings from recent studies indicated that poor communication could lead to aggressive care that may be unwanted by family (Dillworth et al., 2016; Heyland et al., 2015). Poor prognostication by the interdisciplinary team was discussed by both key and general informants. Key informants were frustrated with not understanding the illness trajectory or knowing when death might occur. In a study with heart failure clinic patients, nurses only discussed prognosis “in 38% of conversations, and EOL was discussed in 10%” (Hjelmfors et al., 2015, p. 869).

Families and providers viewed communication among themselves and with the interdisciplinary team as complex and essential, often describing that someone had to shoulder the burden of initiating EOL discussions. During their joint deliberations, ANA and HPNA (ANA, 2017) proposed that nurses, as part of an interdisciplinary team, are responsible for initiating communication about palliative care among families and other interdisciplinary team members.

These complex communication patterns with limited EOLC communication among the family and interdisciplinary team can lead to ethical dilemmas (Cheon et al. 2015). Two key informants had advanced directives and were able to discuss their EOLC wishes with their families. In contrast, eight key informants described poor knowledge of their loved ones’ illness trajectory and EOLC options. A qualitative study conducted by Thoresen and Lilemoen (2016) had similar findings. In a nursing home in Norway, residents and their families were considered an “intertwined unit” (p. 5) and residents wanted their family present for conversations regarding their medical treatment. Additionally, Seccareccia et al.’s (2015) qualitative research reported that communication is essential to quality EOLC as well as family satisfaction. Researchers

found that communicating patients' and families' EOLC expectations and keeping patients, families, and the interdisciplinary care team members informed of these expectations alleviated gaps that could potentially lead to ethical dilemmas from lack of communication (Pattison, Ogara, & Wigmore, 2015 coming from sandy).

This study identified the need for members of the interdisciplinary team to be respectful of generic/folk care and provide culturally congruent professional care. Experts in palliative care support the need for healthcare provider EOLC education, coordinated communication among providers, and culturally sensitive communication patterns that support FDM at EOL (Lynch, 2013; Schreibeis-Baum et al, 2016).

Policy Implications

Policy implications relevant to FDM at EOL include addressing the education needs of healthcare providers, families, and communities. There is a clear need to educate healthcare providers about the EOLC continuum from diagnosis through curative care, palliative care, and death (Figure 1, Appendix A); develop comfort with death as a natural part of life; and learn culturally appropriate communication patterns that facilitate early conversations regarding EOLC wishes. EOLC education partnerships with community members (using train-the-trainer models) could facilitate a culture where people communicate their EOLC wishes with families and healthcare providers before illness occurs (Dobrof, Heyman, & Greenberg, 2011; Mixer et al., 2014).

Four elements limit access to EOLC care for people with life-limiting illness, and essential support for families: the Medicare hospice restrictions of six months or less to live and the inability of persons to continue curative care with hospice care, poor

prognostication by healthcare providers (Mazanec et al., 2009; Myatra et al., 2014; NHPCO, 2015; Wallace, 2015), and the requirement that a physician gatekeeper provide hospice certification. Policies that support a seamless provision of EOLC on a continuum from diagnosis to death is required to accommodate rural Appalachian persons as they move on their illness trajectory from aggressive curative care to death (Figure 1, Appendix A). Additionally, providing care on a continuum may help address the negative stigma some families associate with hospice care (Schreibers-Baum et al., 2016). One strategy to address limited hospice access due to the physician gatekeeper requirement is to approve a policy allowing advance practice nurses to certify patients for hospice admission (ANA, 2017; Wallace, 2015b; Behringer & Krishnan, 2011).

Recommendations for Future Research

This study could be replicated with other vulnerable cultural groups to determine the similarities and differences that support FDM at EOL. Research that implements and evaluates the proposed decisions and actions could help interdisciplinary team members provide culturally congruent EOLC. Additional research is necessary to understand further the influence faith, faith leaders, and faith communities in rural Appalachian have on FDM at EOL.

Reflections of the Study

The researcher is an acute care nurse practitioner who has practiced within the context of EOL decision making in rural Appalachia for 31 years. Such experience facilitated her building trust with patients and families, enabling her to move quickly from stranger to trusted friend (Wehbe-Alamah & McFarland, 2015). Gatekeepers expedited recruitment of both key and general informants. The researcher's mentor was invaluable

in assisting with using the CCT, the ethnonursing method, the Sunrise Enabler as well as reflecting on the findings. Journaling and bracketing facilitated the research process by making the researcher more aware of her potential biases and the informant's feelings. While it was an honor to hear people's EOL stories, it also was emotionally and spiritually taxing. Therefore, it was essential for the researcher to care for herself during the intense time of interviewing informants and analyzing data. Care included physical exercise, eating nutritiously, talking with her mentor, and continuing to journal.

Limitations

This study is limited by its geography. The informants were recruited from a small region in rural Appalachia. Therefore, caution should be taken when considering transferability of findings. As a rural Appalachian, the researcher holds emic views; however, she took great care to journal and bracket potential biases. In addition, the research mentor listened to digital interviews, reviewed transcripts, and confirmed coding.

Conclusion

The CCT and ethnonursing method, a naturalistic and ethnographic paradigm, provided an appropriate lens for discovery in the study. These findings contribute to the body of transcultural nursing, interdisciplinary team, EOL, and family care knowledge. These findings addressed a gap in the literature by discovering the culture care expressions, patterns, and practices of rural Appalachian persons and FDM at EOL. Themes abstracted addressed family, communication, education, economics, and comfort concerns. This study provided important insight into the EOL decision-making process of rural Appalachians that ultimately may help improve access to palliative and

hospice care for this underserved population, thereby contributing to a dignified death for dying persons and their families. The recommendations for nurses and other interdisciplinary team members may help reduce health disparities for rural Appalachians and promote meaningful culturally congruent EOLC.

List of References

- Abendroth, M., & Flannery, J. (2006). Predicting the risk of compassion fatigue: A study of hospice nurses. *Journal of Hospice & Palliative Nursing*, 8(6), 346–356.
doi:10.1097/00129191-200611000-00007
- Abramson, R., & Haskell, J. (2006). Introduction. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (1st ed., pp. XVIII–XXVII). Knoxville, TN: The University of Tennessee Press.
- Ahijevych, K., Kuun, P., Christman, S., Wood, T., Browning, K., & Wewers, M. E. (2003). Beliefs about tobacco among Appalachian current and former users. *Applied Nursing Research*, 16(2), 93–102. doi:10.1016/S0897-1897(03)00009-0
- Ali, S. R., & McWhirter, E. H. (2006). Rural Appalachian youth's vocational/educational postsecondary aspirations applying social cognitive career theory. *Journal of Career Development*, 33(2), 87–111. doi:10.1177/0894845306293347
- Ali, S. R., & Saunders, J. L. (2006). College expectations of rural appalachian youth: An exploration of social cognitive career theory factors. *Career Development Quarterly*, 55(1), 38–51. doi:10.1002/j.2161-0045.2006.tb00003.x
- Ali, S. R., & Saunders, J. L. (2009). The career aspirations of rural Appalachian high school students. *Journal of Career Assessment*. doi:10.1177/1069072708328897
- American Nurses Association. (2017). *Call for action: Nurses lead and transform palliative care*. Retrieved from <http://www.nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/Palliative-Care-Call-for-Action>

- Appalachian Regional Commission. (2013). *Poverty rates, 2009–2013: Appalachian Tennessee*. Retrieved from http://www.arc.gov/reports/region_report.asp?FIPS=47999&REPORT_ID=60
- Appalachian Regional Commission. (2016). *The Appalachian region*. Retrieved from http://www.arc.gov/appalachian_region/TheAppalachianRegion.asp
- Armstrong, B., Jenigiri, B., Hutson, S. P., Wachs, P. M., & Lambe, C. E. (2012). The Impact of a palliative care program in a rural Appalachian community hospital: A quality improvement process. *The American Journal of Hospice & Palliative Care*. doi:10.1177/1049909112458720
- Bainbridge, D., Seow, H., & Sussman, J. (2016). Common components of efficacious in-home end-of-life care programs: A review of systematic reviews. *Journal of the American Geriatrics Society*, 64(3), 632–639. doi:10.1111/jgs.14025
- Baird, P. (2015). Spiritual care intervention. In B. R. Ferrell, N. Coyle, & J. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (4th ed., pp. 546–553). New York, NY: The Oxford University Press.
- Bakitas, M., Clifford, K. N., Dionne-Odom, J. N., & Kvale, E. A. (2015). Rural palliative care. In B. Ferrell, C. A. Coyne, & J. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (4th ed., pp. 812–823). New York, NY: Oxford University Press.
- Barish, R., & Snyder, A. E. (2008). Use of complementary and alternative healthcare practices among persons served by a remote area medical clinic. *Family & Community Health*, 31(3), 221–227. doi:10.1097/01.FCH.0000324479.32836.6b
- Batteau, A. (1982). Mosbys and broomsedge: The semantics of class in an Appalachian kinship system. *American Ethnologist*, 9(3), 445–466.

- Behringer, B., & Krishnan, K. (2011). Understanding the role of religion in cancer care in Appalachia. *The Southern Medical Journal*, 104(4), 295–296.
doi:10.1097/SMJ.0b013e3182084108
- Bekelman, D. B., Rabin, B. A., Nowels, C. T., Sahay, A., Heidenreich, P. A., Fischer, S. M., & Main, D. S. (2016). Barriers and facilitators to scaling up outpatient palliative care. *Journal of Palliative Medicine*, 19(4), 456–459.
doi:10.1089/jpm.2015.0280
- Bell Meisenhelder, J., D'Ambra, C., & Jabaley, T. (2016). Spiritual coping at the end of life: A case study of a college. *Journal of Hospice & Palliative Nursing*, 18(1), 66–73. doi:10.1097/NJH.0000000000000214
- Best, M., & Wood, C. W. (2006). Agriculture. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 395–439). Knoxville, TN: The University of Tennessee Press.
- Bishara, M. N. (1987). Technical careers for women: A perspective from rural Appalachia. *Bulletin of Science Technology & Society*, 7(1–2), 260–272.
doi:10.1177/027046768700700145
- Blackler, L. (2016). Compromised autonomy: When families pressure patients to change their wishes. *Journal of Hospice & Palliative Nursing*, 18(4), 184–191.
doi:10.1097/NJH.0000000000000264
- Blinderman, C. D., & Billings, J. A. (2015). Comfort care for patients dying in the hospital. *The New England Journal of Medicine*, 373(26), 2549–2561.
doi:10.1056/NEJMr1411746

- Bonura, D., Fender, M., Roesler, M., & Pacquiao, D. F. (2001). Culturally congruent end-of-life care for Jewish patients and their families. *Journal of Transcultural Nursing*, 12(3), 211–220.
- Brown, J. W., & May, B. A. (2005). Rural older Appalachian women's formal patterns of care. *Southern Online Journal of Nursing Research*, 2(6), 2–21.
- Burkett, G. L., Mulcahy, R. P., & Zahorik, P. M. (2006). Health. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 1631–1677). Knoxville, TN: The University of Tennessee Press.
- Burkhardt, M. A. (1993). Characteristics of spirituality in the lives of women in a rural Appalachian community. *Journal of Transcultural Nursing*, 4(2), 12–18.
doi:10.1177/104365969300400203
- Burns, S. L., Scott, S. L., & Thompson, D. J. (2006). Family and community. In R. Abramson & J. Haskell (Eds.), *Encyclopeida of Appalachia* (pp. 149–197). Knoxville, TN: The University of TN Press.
- Bužgová, R., & Sikorová, L. (2015). Association between quality of life, demographic characteristics, physical symptoms, and unmet needs in inpatients receiving end-of-life care. *Journal of Hospice & Palliative Nursing*, 17(4), 325–332.
doi:10.1097/NJH.0000000000000170
- Campbell, C. L., & Ash, C. R. (2007). Keeping faith. *Journal of Hospice & Palliative Nursing*, 9(1), 31–41. doi:10.1097/00129191-200701000-00008
- Campbell, C. L., Boyer, D. E., Campbell, L. C., & Rovnyak, V. (2012). Pain management topics of interest for nurses in rural Appalachia. *Journal of Continuing Education in Nursing*, 43(6), 267–276. doi:10.3928/00220124-

20111215-01

Campbell, C. L., Merwin, E., & Yan, G. (2009). Factors that influence the presence of a hospice in a rural community. *Journal of Nursing Scholarship*, 41(4), 420–428.

doi:10.1111/j.1547-5069.2009.01310.x

Campbell, C. L., Williams, I. C., & Orr, T. (2010). Factors that impact end-of-life decision making in African Americans with advanced cancer. *Journal of Hospice & Palliative Nursing*, 12(4), 214–224.

Carlson, M. D. A., Bradley, E. H., Du., Q., & Morrison, R. S. (2010). Geographic access to hospice in the United States. *Journal of Palliative Medicine*, 13(11), 1331–1338. doi:10.1089/jpm.2010.0209

Carpenter, R. (2015). Harm/loss, threat, and challenge of living with diabetes for persons from rural Appalachia: A qualitative study. *Holistic Nursing Practice*, 29(5), 323–329. doi:10.1097/HNP.0000000000000103

Carter, J. (2009). Reflections on a rotation in Appalachia. *Family Medicine*, 41(7), 470–471.

Centers for Disease Control and Prevention (CDC). (2015). *Mortality data*. Retrieved from <http://www.cdc.gov/nchs/deaths.htm>

Centers for Medicare & Medicaid Services. (2016a). *Final fiscal year 2017 payment and policy changes for the medicare hospice benefit (CMS-1652-F)*. Retrieved from <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2016-Fact-sheets-items/2016-07-29-2.html>

Centers for Medicare & Medicaid Services. (2016b). *Medicare care choices model*. Retrieved from <https://innovation.cms.gov/initiatives/Medicare-care-Choices/>

- Cheon, J., Coyle, N., Wiegand, D. L., & Welsh, S. (2015). Ethical issues experienced by hospice and palliative nurses. *Journal of Hospice and Palliative Nursing*, 17(1), 7–13. doi:10.1097/NJH.0000000000000129
- Chi, N. C., & Demiris, G. (2017). Family caregivers' pain management in end-of-life care: A systematic review. *American Journal of Hospice and Palliative Medicine*, 34(5), 470–485. doi:10.1177/1049909116637359
- Colaberdino, V., Marshall, C., DuBose, P., & Daitz, M. (2016). Economic impact of an advanced illness consultation program within a medicare advantage plan population. *Journal of Palliative Medicine*, 19(6), 622–625. doi:10.1089/jpm.2015.0423
- Colyer, D. (2001). Changes in Appalachian agriculture: 1965-2000. *Journal of Appalachian Studies*, 7(2), 349–374.
- Coyle, N. (2014). Palliative care, hospice care, and bioethics. *Journal of Hospice & Palliative Nursing*, 16(1), 6–14. doi:10.1097/NJH.0000000000000032
- Coyle, N. (2015). Introduction to palliative nursing care. In B. Ferrell, N. Coyle, & J. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (4th ed., pp. 3-10). New York, NY: Oxford University Press.
- Coyne, C. A., Demian-Popescu, C., & Friend, D. (2006). Social and cultural factors influencing health in southern West Virginia: A qualitative study. *Preventing Chronic Disease*, 3(4), A124.
- Cronin, J., Arnstein, P., & Flanagan, J. (2015). Family members' perceptions of most helpful interventions during end-of-life care. *Journal of Hospice & Palliative Nursing*, 17(3), 223–228. doi:10.1097/NJH.0000000000000151

- Daly, D., & Matzel, S. C. (2013). Building transdisciplinary approach to palliative care in an acute care setting. *Omega (Westport)*, 67(1-2), 43–51.
- DeYoung, A. J., Glover, M., & Herzog, M. J. R. (2006). Education. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 1517–1561). Knoxville, TN: The University of Tennessee Press.
- Diddle, G., & Denham, S. A. (2010). Spirituality and its relationships with the health and illness of Appalachian people. *Journal of Transcultural Nursing*, 21(2), 175–182. doi:10.1177/1043659609357640
- Dillworth, J., Dickson, V. V., Mueller, A., Shuluk, J., Yoon, H. W., & Capezuti, E. (2016). Nurses' perspectives: Hospitalized older patients and end-of-life decision-making. *Nursing in Critical Care*, 21(2), e1–e11. doi:10.1111/nicc.12125
- Dionne-Odom, J. N., & Bakitas, M. (2012). Why surrogates don't make decisions the way we think they ought to: Insights from moral psychology. *Journal of Hospice & Palliative Nursing*, 14(2), 99–106. doi:10.1097/NJH.0b013e31823cc791
- Dobrof, J., Heyman, J. C., & Greenberg, R. M. (2011). Building on Community Assets to Improve Palliative and End-of-Life Care. *Journal of Social Work in End of Life & Palliative Care*, 7(1), 5–13. doi:10.1080/15524256.2011.548044
- Dorgan, H. (2006). Religion. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 1281–1359). Knoxville, TN: The University of Tennessee Press.
- Dose, A. M., Leonard, B., Peden McAlpine, C., & Kreitzer, M. J. (2014). The meaning of spirituality at the end of life. *Journal of Hospice & Palliative Nursing*, 16(3), 158–164. doi:10.1097/NJH.0000000000000041

- Dose, A. M., Rhudy, L. M., Holland, D. E., & Olson, M. E. (2011). The experience of transition from hospital to home hospice: Unexpected disruption. *Journal of Hospice & Palliative Nursing*, 13(6), 394–402.
doi:10.1097/NJH.0b013e318227f8f2
- Embler, P. J. (2012). *End of life culture care expressions, meanings, patterns, and practices among Yup'ik eskimo*. (Doctoral dissertation), Retrieved from http://trace.tennessee.edu/cgi/viewcontent.cgi?article=2422&context=utk_graddis
[S](#)
- Issue, B. M., Beaton, A., Hull, C., Belfrage, J., Thompson, S., Meachen, M., & Gillespie, J. A. (2015). Living with economic hardship at the end of life. *BMJ Supportive & Palliative Care*, 5(2), 129–137. doi:10.1136/bmjspcare-2013-000460
- Ferrell, B., Grant, M., & Sun, V. (2015). Nursing research. In B. Ferrell, N. Coyle, & J. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (4th ed., pp. 1028–1038). New York, NY: Oxford University Press.
- Finucane, T. E. (1999). How gravely ill becomes dying: A key to end-of-life care. *Journal of the American Medical Association*, 282(17), 1670–1672.
doi:10.1001/jama.282.17.1670
- Garrido, M. M., Prigerson, H. G., Bao, Y. H., & Maciejewski, P. K. (2016). Chemotherapy use in the months before death and estimated costs of care in the last week of life. *Journal of Pain and Symptom Management*, 51(5), 875–881.
doi:10.1016/j.jpainsymman.2015.12.323

- Gates, Marie (1988). Care and cure meanings, experiences and orientations of persons who are dying in hospital and hospice setting. (Doctoral dissertation, Wayne State University).
- Gobble, C. D. (2009). The value of story theory in providing culturally sensitive advanced practice nursing in rural Appalachia. *Online Journal of Rural Nursing and Health Care*, 9(1), 94–105.
- Gotts, E. E., & Purnell, R. F. (1986). Families and schools in rural Appalachia. *American Journal of Community Psychology*, 14(5), 499–520. doi:10.1007/bf00935355
- Grant, H. S., & Scott, K. K. (2015). An introduction and overview of social model hospice care. *Journal of Hospice & Palliative Nursing*, 17(5), 456–461. doi:10.1097/NJH.0000000000000186
- Hendrickson, K. A. (2012). Student resistance to schooling: Disconnections with education in rural Appalachia. *High School Journal*, 95(4), 37–49.
- Hennen, J. C., & Lewis, R. L. (2006). Labor. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 552–609). Knoxville, TN: The University of Tennessee Press.
- Henry, B., & Scales, D. C. (2012). Ethical challenges in conducting research on dying patients and those at high risk of dying. *Accountability in Research-Policies and Quality Assurance*, 19(1), 1–12. doi:10.1080/08989621.2011.622173
- Hess, D. (2013). Faith healing and the palliative care team. *Journal of Social Work in End Life & Palliative Care*, 9(2–3), 180–190. doi:10.1080/15524256.2013.794054
- Heyland, D. K., Dodek, P., Mehta, S., Cook, D., Garland, A., Stelfox, H. T., . . . Canadian Researchers at End of Life Network. (2015). Admission of the very

- elderly to the intensive care unit: Family members' perspectives on clinical decision-making from a multicenter cohort study. *Palliative Medicine*, 29(4), 324–335. doi:10.1177/0269216314566060
- Hjelmfors, L., van der Wal, M. H. L., Friedrichsen, M. J., Mårtensson, J., Strömberg, A., & Jaarsma, T. (2015). Patient-nurse communication about prognosis and end-of-life care. *Journal of Palliative Medicine*, 18(10), 865–871. doi:10.1089/jpm.2015.0037
- Holt, J., & Reeves, J. S. (2001). The meaning of hope and generic caring practices to nurture hope in a rural village in the Dominican Republic. *Journal of Transcultural Nursing*, 12(2), 123–131.
- Howe, E. G. (2014). How to help patients and families make better end-of-life decisions. *Journal of Clinical Ethics*, 25(2), 83–95.
- Huff, M. B., Weisenfluh, S., Murphy, M., & Black, P. J. (2006). End-of-life care and social work education: What do students need to know? *Journal of Gerontological Social Work*, 48(1–2), 219–231. doi:10.1300/J083v48n01_15
- Hufford, M. (2006). Folklore and folklife. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 844–909). Knoxville, TN: The University of Tennessee Press.
- Huttlinger, K. (2013). People of Appalachian heritage. In L. D. Purnell (Ed.), *Transcultural health care: A culturally competent approach* (4th ed., pp. 137–158). Philadelphia: F.A. Davis.
- Institute of Medicine (IOM). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Retrieved from

[https://iom.nationalacademies.org/~media/Files/Report Files/2014/EOL/Report Brief.pdf](https://iom.nationalacademies.org/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf)

- Institute of Medicine (IOM). (2015). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press. Retrieved from <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>
- Izumi, S., & Van Son, C. (2016). "I didn't know he was dying": Missed opportunities for making end-of-life care decisions for older family members. *Journal of Hospice & Palliative Nursing*, 18(1), 74–81. doi:10.1097/NJH.0000000000000215
- Izumi, S., Nagae, H., Sakurai, C., & Imamura, E. (2012). Defining end-of-life care from perspectives of nursing ethics. *Nursing Ethics*, 19(5), 608–618. doi:10.1177/0969733011436205
- Kavanaugh, K. L., & Campbell, M. L. (2014). Conducting end-of-life research: Strategies for success. *Nursing Science Quarterly*, 27(1), 14–19. doi:10.1177/0894318413509711
- Khosla, N., Washington, K., Shaunfield, S., & Aslakson, R. (2017). Communication challenges and strategies of U.S. health professionals caring for seriously ill South Asian pts and their families. *Journal of Palliative Medicine*, 20(6), 611–617. doi:10.1089/jpm.2016.0167
- Kirchhoff, K. T., & Faas, A. I. (2007). Family support at end of life. *AACN Advanced Critical Care*, 18(4), 426–435.
- Krishnan, P., Williams, H., & Maharaj, I. (2015). Patterns of end-of-life care: Place of death and terminal hospitalization among long term care residents. *Journal of*

Hospice & Palliative Nursing, 17(2), 133–142.

doi:10.1097/NJH.0000000000000136

Lee, R. C. (2012). Family homelessness viewed through the lens of health and human rights. *Advances in Nursing Science*, 35(2), E47–E59.

doi:10.1097/ANS.0b013e3182537432

Leininger, M. (1997). Overview of the theory of culture care with the ethnonursing research method. *Journal of Transcultural Nursing*, 8(2), 32–52.

doi:10.1177/104365969700800205

Leininger, M. (2002a). Culture care theory: A major contribution to advance transcultural nursing knowledge and practices. *Journal of Transcultural Nursing*, 13(3), 189–192. doi:10.1177/10459602013003005

Leininger, M. (2002b). The theory of culture care and the ethnonursing research method. In M. Leininger & M. R. McFarland (Eds.), *Transcultural Nursing: Concepts, theories, research, and practice* (3rd ed., pp. 71–98). New York, NY: McGraw Hill Medical Publishing Division.

Leininger, M. (2006a). Culture care diversity and universality theory and evolution of the ethnonursing method. [Revised reprint]. In M. M. Leininger & M. R. McFarland (Eds.), *Culture care diversity & universality: A worldwide nursing theory* (2nd ed., pp. 1–42). New York, NY: Jones and Bartlett.

Leininger, M. (2006b). Ethnonursing: A research method with enablers to study the theory of culture care [Revised reprint]. In M. Leininger & M. R. McFarland (Eds.), *Culture care diversity and universality: A worldwide theory of nursing* (2nd ed, pp. 43–82). New York, NY: Jones & Bartlett.

- Lewis, S., Messner, R., & McDowell, W. A. (1985). An unchanging culture. *Journal of Gerontological Nursing*, 11(8), 20–26. doi:10.3928/0098-9134-19850801-07
- Lozier, J., & Althouse, R. (1975). Retirement to the porch in rural Appalachia. *International Journal of Aging & Human Development*, 6(1), 7–15.
- Lynch, S. (2013). Hospice and palliative care access issues in rural areas. *American Journal of Hospice and Palliative Medicine*, 30(2), 172–177.
doi:10.1177/1049909112444592
- MacAvoy, S., & Lippman, D. T. (2001). Teaching culturally competent care: Nursing student experience rural Appalachia. *Journal of Transcultural Nursing*, 12(3), 221–227.
doi:10.1177/104365960101200306
- MacDonald, R. C., Weeks, L. E., & McInnis-Perry, G. (2011). End-of-life healthcare decision-making: The intermediary role of the ethicist in supporting family caregivers and health professionals. *Work (Reading, Mass.)*, 40(1), 63–73.
- Mazanec, P., & Panke, J. T. (2015). Cultural considerations in palliative care. In B. Ferrell, N. Coyle, & J. Paice (Eds.), *Oxford textbook of palliative nursing* (4th ed., pp. 580–591). New York, NY: Oxford University Press.
- McFarland, M. R., Mixer, S. J., Wehbe-Alamah, H., & Burk, R. (2012). Ethnonursing: A qualitative research method for studying culturally competent care across disciplines. *International Journal of Qualitative Methods*, 11(3), 259–279.
- McFarland, M. R., & Wehbe-Alamah, H. B. (2015). The theory of culture care diversity and universality. In M. R. McFarland & H. B. Wehbe-Alamah (Eds.), *Culture care*

diversity and universality: A worldwide nursing theory (3rd ed., pp. 1–31).

Burlington, MA: Jones & Bartlett Learning, LLC.

Medicare Payment Advisory Commission. (2015). *Chapter 12: Hospice services*.

Retrieved from <http://www.medpac.gov/docs/default-source/reports/chapter-12-hospice-services-march-2015-report-.pdf?sfvrsn=0>

Melhado, L. W., & Byers, J. F. (2011). Patients' and surrogates' decision-making characteristics: Withdrawing, withholding, and continuing life-sustaining treatments. *Journal of Hospice & Palliative Nursing*, 13(1), 16–30 15p.
doi:10.1097/NJH.0b013e318207a6fe

Mixer, S. J., Fornehed, M. L., Varney, J., & Lindley, L. C. (2014). Culturally congruent end-of-life care for rural Appalachian people and their families. *Journal of Hospice & Palliative Nursing*, 16(8), 526–535.
doi:10.1097/NJH.0000000000000114

Montgomery, M. (2006). Language. In R. Abramson & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 999–1033). Knoxville, TN: The University of Tennessee Press.

Morris, E. J. (2012). Respect, protection, faith, and love: Major care constructs identified within the subculture of selected urban African American adolescent gang members. *Journal of Transcultural Nursing*, 23(3), 262–269.
doi:10.1177/1043659612441014

Myatra, S. N., Salins, N., Iyer, S., Macaden, S. C., Divatia, J. V., Muckaden, M., . . .

Mani, R. K. (2014). End-of-life care policy: An integrated care plan for the dying. *Indian Journal of Critical Care Medicine*, 18(9), 615–635. doi:10.4103/0972-5229.140155

National Center for Health Statistics. (2010). *Health, United States, 2010: With special feature on death and dying*. Hyattsville, MD: National Center for Health Statistics.

Retrieved from <http://www.cdc.gov/nchs/data/hus/hus10.pdf>

National Hospice and Palliative Care Organization (NHPCO). (2015a). *NHPCO's Facts and figures: Hospice care in America, 2015 edition*. Retrieved from

http://www.nhpc.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

National Hospice and Palliative Care Organization (NHPCO). (2015b). *History of hospice care*. Retrieved from <http://www.nhpc.org/history-hospice-care>

National Institutes of Health (NIH). (2004). NIH state-of-the-science conference statement on improving end-of-life care. *NIH Consensus and State-of-the-Science Statements*, 21(3). Retrieved from

<https://consensus.nih.gov/2004/2004EndOfLifeCareSOS024PDF.pdf>

National Institutes of Health (NIH). (2014). *Preparing for the end of life*. Retrieved from

<http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html>

National Institute of Nursing Research (NINR). (2013). *Building momentum: The science of end-of-life and palliative care. A review of research trends and*

funding, 1997-2010. Retrieved from

<http://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR-Building-Momentum-508.pdf>

National Institutes of Nursing Research (NINR). (2014). *Spotlight on end-of-life and palliative care research*. Retrieved from

<http://www.ninr.nih.gov/researchandfunding/spotlight-on-end-of-life-research>

- Paskett, E. D., Fisher, J. L., Lengerich, E. J., Schoenberg, N. E., Kennedy, S. K., Conn, M. E., ... Dignan, M. (2011). Disparities in underserved white populations: The case of cancer-related disparities in Appalachia. *The Oncologist*, 16(8), 1072–1081. doi:10.1634/theoncologist.2011-0145
- Pattison, N., O'Gara, G., & Wigmore, T. (2015). Negotiating transitions: Involvement of critical care outreach teams in end-of-life decision making. *American Journal of Critical Care*, 24(3), 232–240. doi:10.4037/ajcc2015715
- Pavlish, C., Brown-Saltzman, K., So, L., Heers, A., & Iorillo, N. (2015). Avenues of action in ethically complex situations. *Journal of Nursing Administration*, 45(6), 311–318. doi:10.1097/NNA.0000000000000206
- Phipps, S. R. (2006). Settlement and migration. In J. Abraham & J. Haskell (Eds.), *Encyclopedia of Appalachia* (pp. 285–345). Knoxville, TN: The University of Tennessee Press.
- Pollard, K., & Jacobsen, L. A. (2011). *The Appalachian region in 2010: A census data overview*. Retrieved from http://www.arc.gov/assets/research_reports/AppalachianRegion2010CensusReport1.pdf
- Presley, C. (2013). Cultural awareness: Enhancing clinical experiences in rural Appalachia. *Nurse Educator*, 38(5), 223–226. doi:10.1097/NNE.0b013e3182a0e556
- Prince-Paul, M., & Daly, B. J. (2015). Ethical considerations in palliative care. In B. Ferrell, N. Coyle, & J. Paice (Eds.), *Oxford Textbook in Palliative Nursing* (4th ed., pp. 987–1001). New York, NY: Oxford University Press.

- QSR International (2017). NVivo (Version 11.4) [computer software]. Burlington, MA.
- Quinn, J. R., Schmitt, M., Baggs, J. G., Norton, S. A., Dombeck, M. T., & Sellers, C. R. (2012). Family members' informal roles in end-of-life decision making in adult intensive care units. *American Journal of Critical Care, 21*(1), 43–51 49p. doi:10.4037/ajcc2012520
- Radwany, S., Albanese, T., Clough, L., Sims, L., Mason, H., & Jahangiri, S. (2009). End-of-life decision making and emotional burden: Placing family meetings in context. *American Journal of Hospice & Palliative Medicine, 26*(5), 376–383. doi:10.1177/1049909109338515
- Riffin, C., Pillemer, K., Chen, E. K., Warmington, M., Adelman, R. D., & Reid, M. C. (2015). Identifying key priorities for future palliative care research using an innovative analytic approach. *American Journal of Public Health, 105*(1), e15–e21. doi:10.2105/AJPH.2014.302282
- Robinson, C. A., Pesut, B., Bottorff, J. L., Mowry, A., Broughton, S., & Fyles, G. (2009). Rural palliative care: A comprehensive review. *Journal of Palliative Medicine, 12*(3), 253–258. doi:10.1089/jpm.2008.0228
- Rowles, G. D. (1991). Changing health culture in rural appalachia: Implications for serving the elderly. *Journal of Aging Studies, 5*(4), 375–389. doi:10.1016/0890-4065(91)90017-m
- Rowles, G. D., & Johansson, H. K. (1993). Persistent elderly poverty in rural appalachia. *Journal of Applied Gerontology, 12*(3), 349–367. doi:10.1177/073346489301200305

Rural Health Information Hub. (2016). *Rural hospice and palliative care*. Retrieved from <https://www.ruralhealthinfo.org/topics/hospice-and-palliative-care>

Saleh, Z. T., Lennie, T. A., Mudd-Martin, G., Bailey, A. L., Novak, M. J., Biddle, M., Moser, D. K. (2015). Decreasing sedentary behavior by 30 minutes per day reduces cardiovascular disease risk factors in rural Americans. *Heart & Lung*, 44(5), 382–386. doi:10.1016/j.hrtlng.2015.06.008

Salyers, K. M., & Ritchie, M. H. (2006). Multicultural counseling: An Appalachian perspective. *Journal of Multicultural Counseling and Development*, 34(3), 130–142. doi:10.1002/j.2161-1912.2006.tb00033.x

Sandelowski, M. (1994). Channel of desire: Fetal ultrasonography in two use-contexts. *Qualitative Health Research*, 4(3), 262–280. doi:10.1177/104973239400400302

Santiago, C., & Abdool, S. (2011). Conversations about challenging end-of-life cases: Ethics debriefing in the medical surgical intensive care unit. *Dynamics*, 22(4), 26–30.

Schoenberg, N. E., Bundy, H. E., Baeker Bispo, J. A., Studts, C. R., Shelton, B. J., & Fields, N. (2015). A rural Appalachian faith-placed smoking cessation intervention. *Journal of Religion & Health*, 54(2), 598–611. doi:10.1007/s10943-014-9858-7

Schreibers-Baum, H. C., Xenakis, L. E., Chen, E. K., Hanson, M., Ahluwalia, S., Ryan, G., & Lorenz, K. A. (2016). A qualitative inquiry on palliative and end-of-life care policy reform. *Journal of Palliative Medicine*, 19(4), 400–407. doi:10.1089/jpm.2015.0296

Seccareccia, D., Wentlandt, K., Kevork, N., Workentin, K., Blacker, S., Gagliese, L. ...

Zimmermann, C. (2015). Communication and Quality of Care on Palliative Care

Units: A Qualitative Study. *Journal of Palliative Medicine*, 18(9), 758–764.

doi:10.1089/jpm.2014.0408

Shell, R., & Tudiver, F. (2004). Barriers to cancer screening by rural Appalachian

primary care providers. *The Journal of Rural Health*, 20(4), 368–373.

doi:10.1111/j.1748-0361.2004.tb00051.x

Simpson, M. R., & King, M. G. (1999). “God brought all these churches together”:

Issues in developing religion-health partnerships in an Appalachian community.

Public Health Nursing, 16(1), 41–49. doi:10.1046/j.1525-1446.1999.00041.x

Steele, R., & Davies, B. (2015). Supporting families in palliative care. In B. Ferrell, N.

Coyle, & J. Paice (Eds.), *Oxford Textbook of Palliative Nursing* (4th ed., pp. 500–514). New York, NY: Oxford University Press.

Stephenson, J. B. (1984). Escape to the periphery - Commodifying place in rural

Appalachia. *Appalachian Journal*, 11(3), 187–200.

Sullivan, S. S., da Rosa Silva, C. F., & Meeker, M. A. (2015). Family meetings at end of

life. *Journal of Hospice & Palliative Nursing*, 17(3), 196-205.

doi:10.1097/NJH.0000000000000147

Teno, J. M., Gozalo, P. L., Bynum, J. P., Leland, N. E., Miller, S. C., Morden, N. E., . . .

Mor, V. (2013). Change in end-of-life care for Medicare beneficiaries: Site of

death, place of care, and health care transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*, 309(5), 470-477.

doi:10.1001/jama.2012.207624

The Rural School Community and Trust. (2014). *Why rural matters 2013-2014: The condition of rural education in 50 states*. Retrieved from

http://www.ruraledu.org/user_uploads/file/2013-14-Why-Rural-Matters.pdf

Thoresen, L., & Lillemoen, L. (2016). "I just think that we should be informed" a qualitative study of family involvement in advance care planning in nursing homes. *BMC Medical Ethics*, 17(1), 72–72.

U.S. Census Bureau. (2015a). *Population and housing unit estimates*. Retrieved from <https://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml#>

U.S. Census Bureau. (2015b). *Quick facts: Tennessee*. Retrieved from <http://www.census.gov/quickfacts/table/PST045215/47,00>

U.S. Census Bureau. (2015c). *Quick facts: United States*. Retrieved from <https://www.census.gov/quickfacts/table/PST045216/00>

U.S. Department of Health and Human Services (USDHHS). (2016a). *HRSA Data Warehouse: HPSA (Health professional shortage area) find*. Retrieved from <http://datawarehouse.hrsa.gov/tools/analyzers/>

U.S. Department of Health and Human Services (USDHHS). (2016b). *HRSA Data Warehouse: MUA (Medically Underserved Area) find*. Retrieved from <http://datawarehouse.hrsa.gov/tools/analyzers/MuaFind.aspx>

United Nations. (2011). *Protect human rights*. Retrieved from <http://www.un.org/en/sections/what-we-do/protect-human-rights/index.html>

Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Malone-Tucker, S., & Silvar, S. (2011). Learning end-of-life care in ICU: Strategies for nurses new to ICU. *Dynamics*, 22(4), 22–25.

- Wallace, C. L. (2015a). Family communication and decision making at the end of life: A literature review. *Palliative & Supportive Care*, 13(3), 815–825.
doi:10.1017/S1478951514000388
- Wallace, C. L. (2015b). Hospice eligibility and election: Does policy prepare us to meet the need? *Journal of Aging & Social Policy*, 27(4), 364–380.
doi:10.1080/08959420.2015.1054234
- Wehbe-Alamah, H. B., & McFarland, M. R. (2015a). The ethnonursing research method. In M. R. McFarland & H. B. Wehbe-Alamah (Eds.), *Culture care diversity and universality: A Worldwide Nursing Theory* (3rd ed., pp. 35–68). Burlington, MA: Jones & Bartlett Learning, LLC.
- Wehbe-Alamah, H. B., & McFarland, M. R. (2015b). Leininger's enablers for use with the ethnonursing research method. In M. R. McFarland & H. B. Wehbe-Alamah (Eds.), *Culture Care Diversity and Universality: A Worldwide Nursing Theory* (3rd ed., pp. 73–99). Burlington, MA: Jones & Bartlett Learning, LLC.
- Wiegand, D. L., & Funk, M. (2012). Consequences of clinical situations that cause critical care nurses to experience moral distress. *Nursing Ethics*, 19(4), 479–487.
doi:10.1177/0969733011429342
- World Health Organization. (2015). *Palliative care: Fact sheet N°402*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>

Appendices

Appendix A

Figures and Tables

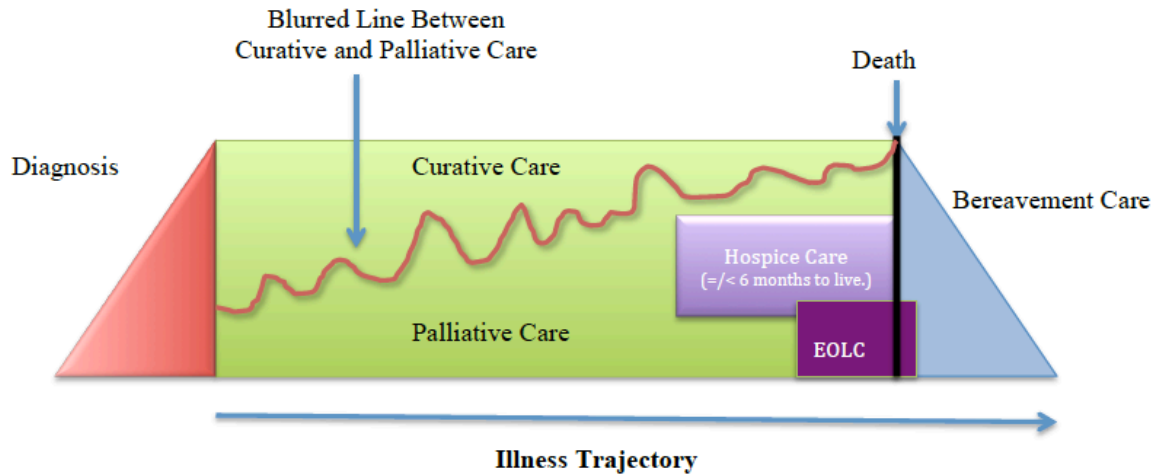


Figure 1. Depiction of the end-of-life care continuum and illness trajectory

Adapted from A new model of palliative care for oncology patients with advanced disease by P. Mazanec, B. J. Daly, E. F. Pitorak, D. Kane, S. Wile, & J. Wolen, 2009, *Journal of Hospice and Palliative Nursing*; 11(6), p. 328 and End-of-life care policy: An integrated care plan for the dying by S. Myatra, N. Salins, S. Iyer, S. C. Macaden, J. Divatia, V. Jigeeshu, M. Muckaden, P. Kulkarni, S. Simha, & R. K. Mani, 2014, *Indian Journal of Critical Care Medicine*, 18(9), p. 619. Used with permission from Wolters Kluwer Health Inc. (Copyright 2009) and Dr. Raj Kumar Mani.

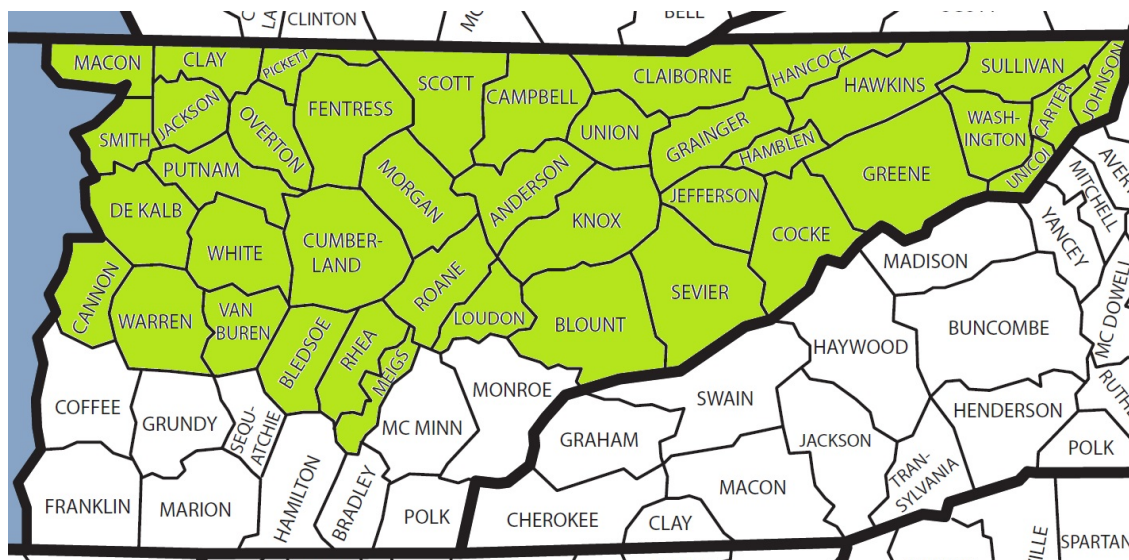


Figure 2. Map of the 40-county informant recruitment area

Adapted from a map of the rural Appalachian region. Appalachian Region Commission (2008). Retrieved from

<https://www.arc.gov/images/appregion/AppalachianRegionCountiesMap.pdf>

Used with permission from the Appalachian Region Commission.

Table 1. Patterns and Quotes for Theme 1

Theme 1: Rural Appalachians make EOL decisions with family	
Recurrent Care Patterns	Salient Informant Quotes
Pattern 1: Rural Appalachian families' awareness of the illness trajectory (diagnosis to death) moves at different rates, which influences EOL decision making.	Key Informants: • "I walked around the computer, and they showed me on the screen and they said 'I'm so,' you know he said 'I'm sorry to tell you. Your dad has a mass on his colon,' and I said, 'I can see spots on his lungs.' I was kind of like in shock, you know and I said 'Oh, you know I hate to hear it, but this explains' I said 'actually, this is what I was kind of expecting.'" • "Ok, we [adult children] want to fill your [dad's] wishes, but... it gets to a crossroads and it does create a rift within the family about how to proceed...As reality sets in for some [family members], it's harder for them to face." • "This is it..." "We're not coming out this time." • "No, you [healthcare provider] don't understand. All we're doing is just buying him a little more time."..."I don't think my dad ever gave up... I think he accepted [life-limiting illness], but I think he always held out hope... he was just at peace about everything." General Informants: • "You know sometimes when the patient's awake, I [nurse] think it's harder for the family to even talk about that [EOL FDM] because they see mama and see a little glimpse of how she used to be." • "So, it comes, I think, as a shock to most people um, when their family member is sick and they're not getting better and often what happens is that they will come in and out of the hospital ah, many times... almost enter a um, ah, revolving door between home and hospital." • "[Healthcare provider] ... very simplistic understanding of clinical medicine and so often patients have unrealistic expectations of what medicine can do for their ailing family members, especially as they get older... just take a pill and you'll be fine."

Table 1. Continued

Theme 1: Rural Appalachians make EOL decisions with family	
Recurrent Care Patterns	Salient Informant Quotes
Pattern 2: Accepting death as a part of life influences rural Appalachian family decision making at EOL	Key Informants: “... he was real comfortable with dying. He was scared of living. He was more scared of living than dying at the end.” “He [person] said ‘We’ve got to get started with this chemo if I’m gonna have any time,’ and ah, she [healthcare provider] said. ‘We can’t do it. It’s too high risk with a chest tube,’ and he said, ‘Well what’s it gonna do? Kill me?’” “... he was a trooper and he was ready to go.” “[taking the palliative radiation/chemo] gave hope to daddy, because I think until the very end, he thought he was gonna be fine... [three weeks later] there wasn’t any um, anything else to do. I mean he was dying.” “I don’t think anybody really expected that he’d only live five weeks.” “‘You know let’s just call this quits,’ [wife describing conversation with husband] but he just, you know we just kept getting up and getting ready to go and just kept on doing.” General Informants: “I think the first step has to be with these families is acceptance of the illness and terminally ill um, because if they don’t accept it, then you’re not gonna get them to accept what they need [HCP discussing speaking to family about hospice care] ... what do you want as family? As this patient, what does she/he want? What are their wishes? Um, and then how can we help them meet those?” [husband speaking to healthcare provider after the death of 40-year-old wife] “I heard what you were saying, but I didn’t want to accept it.”

Table 1. Continued

Theme 1: Rural Appalachians make EOL decisions with family	
Recurrent Care Patterns	Salient Informant Quotes
Pattern 3: Faith influences EOL family decision making.	Key Informants: • “When we were talking about the chemo and... me wanting him to come home... I said ‘Well if you don’t... if we don’t do everything we can, then what am I gonna do. I’ll be all alone,’ and he [spouse] said, ‘I’ll be with you in spirit forever, ‘so I mean he had a, he had a good relationship [faith].” • “I mean he was not worried... I think he was very confident in his salvation and he felt like he had lived a good life...” • “...before [his surgery] he[dad] called my father-in-law who is a minister... my father-in-law came up and baptized him again.” General Informants: • “The patient was able to talk and so he said, ‘Yes, I’m ready to go to the Lord,’ and, and I think once he said that, everybody was ok, even though they were very spiritual and they prayed about it, once they all said that, that seemed to facilitate their decision and he was, he was ready. They were all ready. They accepted it. They knew he was dying.” • “I think sometimes their, their religious beliefs lead them to know what to stop and when it’s time ‘the good Lord will take me and it will be ok,’ and I think on that same dime, some of ‘em think ‘No, I need everything done, so I can stay alive...’” • “I do see that the families that have strong religious beliefs, um can intertwine hospice with that because they know, they seem more settled about the next step in life and you know the end of life process ah, and I’ve noticed others that are not so religious really struggle with hospice cause they’re not ready to hear of any of that.”

Table 2. Patterns and Quotes for Theme 2

Theme 2: Communication encompassing EOL FDM is essential and complex	
Recurrent Care Patterns	Salient informant Quotes
Pattern 1: Rural Appalachians describe that EOL family decision-making communication is a burden on someone (family and interdisciplinary team).	Key Informants: • “It took the pressure off me because I knew, for one thing, I knew he did not want CPR. I knew he did not want to be, have life-saving measures.” • “... we had actually put on his advanced directive, I think we put nutrition for a trial period of seven to 10 days or something general, just cause there could be a circumstance that maybe if you could bounce back from it.” • “I wish that people would talk about it more before it gets to that point... because you know at that point in time... when they think about power of attorney or living will or DNR status, they think if you’re DNR, well `I’m not gonna get any treatment. If I’m hurting, I’m gonna hurt...” • “I think that they, a lot of families think that when you’re power of attorney that you have to fight, you do have the final say when it’s all said and done ,but you need to pick that power of attorney that’s gonna abide by your wishes.” • “You, you’re making decisions for somebody else.” • “... he and I talked about what we thought should be done.” • “[Our Daughter] helped a lot because she understood more of what they were talking about... up until the day of surgery, we still thought it was something simple.” • “I thought... quality of life... would it be the best for him to go through this [further procedures] again and with his age I decided not. Of course, the family was behind me 100%... I discussed everything with [our daughter] ... she knew more medical stuff than anybody I knew.”

Table 2. Continued

Theme 2: Communication encompassing EOL FDM is essential and complex	
Recurrent Care Patterns	Salient informant Quotes
Pattern 1: Rural Appalachians describe that EOL family decision-making communication is a burden on someone (family and interdisciplinary team).	General Informants: • “No one ever wants to give up a loved one, and so that’s the most difficult part of it, is ‘I want to have momma as long as I can have momma. ‘ We have to take the approach then of ‘Well, what kind of life do you want momma to have her last few months?’” • “It’s all about family involvement and how much they understand and that’s when it goes back to what I said at the very beginning, being able to explain to them early on and in terms they understand.” • “... you get extra family members who hadn’t seen ‘em in 15 years, want to come in and say oh no, let’s do everything. I want everything done. Of course, then when they’re unresponsive and can’t talk to you, that’s kind of where it gets a little grey... you know if they hadn’t had that discussion beforehand.” • “You have to stick to your decision you made, because when you decide to make somebody a DNR and take ‘em home or put ‘em in the nursing home, when they’re dying... you just have to know that they got the best care possible, and that you did the best decision you could do. Because you can’t second guess and change it two weeks down the road. You know you’ve got to go with it.”
Pattern 2: Interdisciplinary team members plant seeds for families to consider when making decisions at EOL.	Key Informants: • “... because as the [team] would communicate things to us, if there was a comment or even a single word used in those discussions that could be mistaken as a sliver of hope of recovery, that’s the only thing that [person and extended family] were retaining and they would grab a hold of one piece of information.” • “[Healthcare provider] did a good job explaining it to my dad, and my dad was pretty upset... he sort of processed it and then he was kind of like moving on.” • “I could not get any doctor or anybody at the hospital to give me an idea of how long he might live.”

Table 2. Continued

Theme 2: Communication encompassing EOL FDM is essential and complex	
Recurrent Care Patterns	Salient informant Quotes
Pattern 2: Interdisciplinary team members plant seeds for families to consider when making decisions at EOL.	General Informants: • “We have to explain that we cannot give them any kind of definitive answer but try to give them... a broad picture (predicting time of death).” • “We [providers] go from ‘Oh, we’re gonna do this. We’re gonna do this [move from aggressive care to withdrawal of care]...’ You’re going to get better.’ And then the next thing, we go in we say, ‘Well we’ve tried all that and that all failed’ and so the end result’s gonna be the same. I think that’s the problem with how we do it at this facility compared to maybe how [another facility] does it.” • “I think you have to start the conversation early.” • “If they say ‘No, I just want grandpa to come on home and be...’ then we have to stress about ‘Ok, are you gonna be the only caregiver?’ because we have to tell them ‘This is a big undertaking that you’re trying to bring on yourself...’ It’s not easy because no one knows the day or the hour...what/how much time that person may have...we can’t say that on January 1st or January 31st, grandpa is gonna die.” • “‘This is what we think you need to do and this is the steps to do that.’ It almost has to be like it’s their idea. They’ve come up with it, you know. You put it out there and then they kind of circle around.” • “Sometimes [nurses] have to be very stern with them [person and family] to say this is happening and we’ve got to talk about it. Somebody’s gotta talk about this and I try to leave it up to the family of who talks [about] it with the patient... what does she know or he know and see where they’re all at first...” • “I don’t want to not give them hope, but I also want to be honest with them.” • “I think just approaching the subject with them to see what their wishes are... just lead into it softly and gently, nicely.” • “We need to give them time to process it and discuss it outside of the hospital to where they’re not hearing, the IV pumps and seeing the nurse and so forth and, and try to help them realize that just because we’re recommending this, that it doesn’t mean that we’re going to stop treating or caring.”

Table 2. Continued

Theme 2: Communication encompassing EOL FDM is essential and complex	
Recurrent Care Patterns	Salient informant Quotes
Pattern 3: The concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members.	Key Informants: • Well I[spouse] think what helped it more than anything was um, ah, discussions with [the healthcare provider]. Ah he just laid it on the line as to what it was and how it was gonna be and as far as making the decisions, I think once you start making decisions, the more you make, the easier it gets.” • “I [spouse] just sat down on the bed and I said ‘You know we need to talk about this [palliative treatment] and decide what we need to do because you know it’s ah, I want you to get well and I want you to be at home,’ and um, he said ‘Well, (sigh) maybe we ought to try,’ and ah, so I said ‘Well if that’s what you want to do, that’s what we’re gonna do,’ and that’s what we did.” • “He [person] wanted to go back to the [skilled nursing facility] and tell my mother. He wouldn’t let me tell my mother that he had cancer. I begged him to let me. You know I said ‘Let me break it to her and give her a little time to think about it’...at first, he said yes and then he said ‘No, I’ve changed my mind if anybody’s gonna tell her, it’s gonna be me.’” • There was times that I flat out told... [the healthcare provider], you know when he’s coming off with all of this stuff and of course I’m just like in shock that we’re hearing this is cancer... because we’ve been told it’s not and I just flat out told him ‘You’re gonna have to talk. I am not a nurse right now. I am his daughter. You talk to me like I am his daughter and I know nothing about any of this.’ I said ‘Because I’m having to process all of this.’” • “When I [adult child] first started talking about hospice, I’m not sure if that scared a couple of ‘em [family] a little bit, just the notion of what’s that really gonna mean and, and but pretty soon, they all got on board.” • “After a few days, you know [person] was more open to talking about it, he just wanted to go home. He said ‘I am not going back to the nursing home.’ He was adamant about that. He said ‘I do not want to spend my, what time I have left there.’”

Table 2. Continued

Theme 2: Communication encompassing EOL FDM is essential and complex	
Recurrent Care Patterns	Salient informant Quotes
Pattern 3: The concept of “lay it on the line” characterizes effective communication among family and interdisciplinary team members.	Key Informants continued: • “[Hospice]... talked to us and they talked more to me and my mom and my sister and brother, because ah, my dad had accepted it but he really didn’t want to talk about it. He just, you know um, he knew he was gonna die... he said ‘Ya’ll can decide,’ and ah, so we arranged for hospice and he went home by ambulance in the pouring rain.” • “My dad is saying ‘Ah, let’s go over and pick out some tombstones’... I am saying [to my dad] ‘Shut up,’ because my mother’s falling to pieces.” • “I told [the healthcare provider] I said, ‘I just can’t tell my dad that there’s no hope,’ I said ‘I cannot, I don’t think that’s my job,’ and I said ‘I’m his daughter and I don’t, I don’t think it’s my responsibility to tell him that there’s no hope in this and ah, she said ‘Well, he should have been told a long time ago.’” General Informants: • “Over the years, I’ve seen lots of families that just don’t talk about it [their EOLC wishes].” “The difficult times is either number 1, the patient can’t no longer talk to us. We don’t know their wishes and then you have two or three sets of families. You either have a, a husband that’s got mine, yours and our kids and nobody talks, then you have trouble there.”

Table 3. Patterns and Quotes for Theme 3

Theme 3: Education and economics influence person and FDM at EOL	
Recurrent Care Patterns	Salient informant Quotes
Pattern 1: Rural Appalachian EOL family decision making is influenced by a lack of knowledge about the illness trajectory (diagnosis to death) and EOLC.	Key Informants: • “when this happened, we [family] didn’t understand. None of us understood it, the progression... of... congestive heart failure... so we started grasping it at the end stage and we have some [extended family] that have not grasped the entire process.” • “You know literature [written patient education material] that reinforces the condition [CHF] gives them [families] something more tangible especially when you know if it’s an older population, um, you know not everything sticks sometimes.” • “They [person and extended family] needed constant reinforcement.” • I mean, I don’t know what it [alternative palliative procedure] would have been. There probably isn’t anything, but there might have been something.” • “[Person] with a 6th grade education but still was ‘educated’” General Informants: • “I’m lookin’ around and I see that kind of blank... (chuckles) ... expression. I usually stay after the doctors and just kinda’, y’know, give them [person and family] in laymen’s terms... sometimes it takes a while for them to get it. Sometimes it takes more than three or four conversations... for it to finally sink in... it’s worth continuing to have that talk without being harsh.” • “It’s just a matter of speaking in terms that they understand.” • “...first and foremost, I’m [interdisciplinary team member] not here to tell ‘em what to do, I’m here to educate them on their options and I find out who everybody’s place is in the family and ah, start from there.” • “I think one thing we see is a lot of patient population rural Appalachia... have a poor and probably very simplistic understanding of clinical medicine, and so often patients have unrealistic expectations of what medicine can do for their ailing family members especially as they get older.” • “I think that families believe that medicine perhaps from what they see on TV or what they read about can do miracles almost, continue living until you’re um, 100 years old despite having been a smoker and drinker.”

Table 3. Continued

Theme 3: Education and economics influence person and FDM at EOL	
Recurrent Care Patterns	Salient informant Quotes
Pattern 1: Rural Appalachian EOL family decision making is influenced by a lack of knowledge about the illness trajectory (diagnosis to death) and EOLC.	General Informants continued: • “When someone has a real severe acute illness and they’re on a ventilator for instance and... it’s clear that they have multiplicity of illnesses that just are not going to get better and then we have to face a decision as to how much extra care do we want to give... such as a tracheostomy and going off to another city maybe 100 miles away to live in a long-term care facility where they are mostly just boarded and then we also talk with family members... that if they were to survive that they will not be the person they were before.” • “For me it’s seeing them repeatedly come in the hospital, and, wanting to get better and having to educate them and helping them understand that what they’ve got is really, uh, a terminal disease
Pattern 2: Rural Appalachian family decision making at EOL is influenced by economics, the need to choose “the lesser of two evils.”	Key Informants: • “...my dad’s very practical... He talked to his attorney because you know if you go to the nursing home and you’re there long term, eventually it all comes back around and they’ll take your property [the farm].” • “They’re not like millionaires. My mother needs to sell her house. I mean we have enough for her to live at [the skilled nursing facility] ... but it’s not infinite “ • “I couldn’t have afforded to probably, it would have been rough, because all mother had was her social security and... a little money saved... to take care of her in the nursing home... when that was gone... I still took care of extra things...she needed as far as clothes or extra food or Coca-colas. (laugh)... if I had to give up my job at that time...it would have been a hardship.” “ • I didn’t worry about money... by the time he got sick and died, I had accumulated some money, and of course I had my savings, my 401K... I was already drawing my social security and I was entitled to draw part of his pension... money never crossed my mind.”

Table 3. Continued

Theme 3: Education and economics influence person and FDM at EOL	
Recurrent Care Patterns	Salient informant Quotes
Pattern 2: Rural Appalachian family decision making at EOL is influenced by economics, the need to choose “the lesser of two evils.”	General Informants: • [Interdisciplinary team member speaking] “I’d like for daddy to be able to go here and have this kind of care, but we can’t afford that.’ ‘I’ve got to work, but if I stay home with him, then we’re not gonna have any money.’ So, you know it’s one of those like a vicious cycle. I want him to go here and get the care, but I can’t afford it. But then I can’t afford to stay home with him either.” • “If he goes here... will they take the family farm, because I don’t have the money to pay.’ But that’s a big fear of theirs... I think it’s a legitimate fear because you know when that family member has passed on, they still have to have a place to live.” • “Sometimes we get ready to send somebody home... no running water, they don’t have electricity, so we take those things for granted so we have to really... see what the scenario is, because sometimes, that’s not a possibility, a hospice situation.” • “...we [healthcare provider speaking] do have some funding, it does help... even with the funding, that only lasts for so long. These patients have to be on this treatment, sometimes, for life... Most of the time, for life... we can give ‘em three to six months or even a year if they’re lucky, of free drug. But what about after that?” • “It’s almost like a lesser of two evils. I see this all the time, if mom has a home, it’s paid for, and you know she’s sick. The family is wanting her to get the best [care] she can get. Their torn between... if she goes in a nursing home from now on, there goes all the property and all the land and mom’s worked hard all her life, so what now?” • “That really was his biggest concern because he was drowning in debt and did not want to leave that... for his children and he knew he was dying, so getting hospice involved earlier was a big, financial motivator for him.”

Table 4. Patterns and Quotes for Theme 4

Theme 4: Comfort for living while dying	
Recurrent Care Patterns	Salient informant Quotes
Universal pattern: Folk (emic) care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy.”	Key Informants: • “It’s hard to let go but... you want them comfortable.” • “There was a couple men that from their church that always visited him every week or two at home, even though he hadn’t been able to go to church.” • “It [communion] was real sweet um, [with] Bible verses. I said ‘Dad, was that ok?’ and he said ‘I love it.’” [spouse was uncomfortable with the communion service] • “Three or four weeks before he[died], he thought a Subway sandwich sounded good and so my brother went and got it for him... he told me he’d like donuts and I got ‘em... ..” • “My sister was really upset that we weren’t sitting right there with him [when dad died]. I said ‘You know what? Maybe he needed us to all be gone from the room, before he could go.’” • “I remember the next day after the chemo, he said ah, ‘I think I could run a marathon’ and he called my husband he said ‘Get that tractor going. We’re gonna plant our garden.’” • “He was just determined he was gonna walk, he was gonna drive... He did not think he would be able to do anything again... I think that’s what he wanted to hold on to and... was why going home was so important to him.” • “My dad was thrilled that he lived eight months. He went home thinking he was gonna live two weeks. We had our Thanksgiving and our Christmas [early], because we weren’t gonna have him at Christmas.” • “... don’t think my dad ever gave up... because the day before he passed away, I had friends say at the funeral home, ‘I saw your dad the day before at the grocery store.’” • “I had decorated... big time for Christmas and he was excited when we got home. We had a good Christmas that year.” • “He could look out the window and see the cattle and... the guy that was helping him... came by quite often and would tell ‘em that everything was going smooth... so he still had ah, some control of his life.” • [Spouse said] “... Jesus drank wine, why can’t we drink wine?” • “...he just felt like things were just going on like normal.” • “The gospel... or the Christian singings... she enjoyed that.” • “[Mother] looked forward to Sundays with her grandchildren... loved Coca-Cola.”

Table 4. Continued

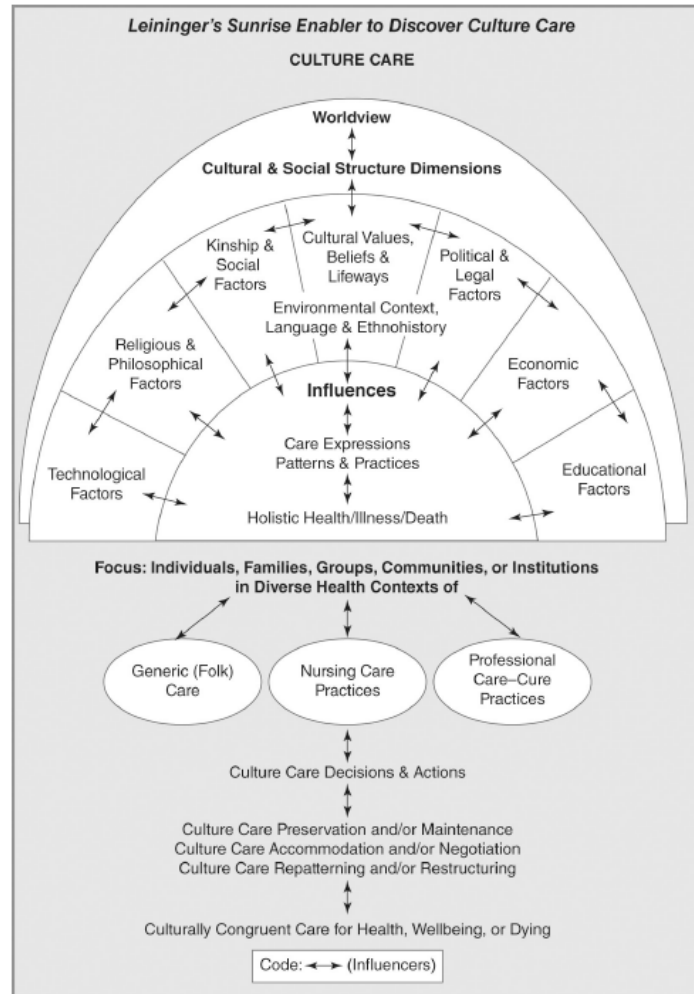
Theme 4: Comfort for living while dying	
Recurrent Care Patterns	Salient informant Quotes
Universal pattern: Folk (emic) care for rural Appalachian families making decisions at EOL meant experiencing “a sense of normalcy.”	General Informants: • “I think some of it’s... just the way they were raised. You know [we] never went to the hospital... always fix things at home...” • “I have participated in patients being baptized in the hospital that were given... news that they don’t have long to live... you know we accommodate ‘em and that forms a bond with ‘em.” • “They had some... herb... some tonic they had to heat up and different things...” • “They kind of choose... ‘I want to go home and do my herbal medicines that I’ve done and not take pain medicine and I know I’m gonna die and I don’t want anybody to come around...” • “I think there’s in rural Appalachia... a lot of these folk remedies that have been handed on down and people ah, almost feel... as though they are insulting their older people or their heritage if they don’t try those first.”
Diverse pattern: Some rural Appalachian families felt hospice care was helpful and some did not.	Key informants: • “We... only had the hospice care for about a week and half.” • “I liked everybody I dealt with from Hospice, every last one of ‘em.” “I thought Hospice was wonderful. I would not, I cannot imagine having to go through that without them... [but] My mom still thinks that hospice killed him.” General informants • “I’ll hear patients say “My cousin John went home with hospice and died that next day.” • “I think just the reputation that hospice has in general (negative reputation creates a barrier for referral).” • “I think most of the people whose ever had hospice, is a positive... it’s usually... better.” • “So maybe hospice does not have to be abou... dying today. It should be about dying with dignity when your time comes.” • “It can’t be called ‘hospice care.’ It’s either pain management or comfort care, but it can’t be hospice.” • “I think it’s a negative cause once you put that [hospice] out there, then, that’s what that family associates with you for a while... you brought this up... that’s kind of a touchy subject and it’s very much on their minds.” • “I think hospice has such a stigma related to it that they feel like and I’ve heard it a thousand times, ‘Well you’re just gonna let ‘em die now.’”

Table 5. Recommended Nursing/Interdisciplinary Team Decisions and Actions

Culture Care Preservation/Maintenance
• Maintain respect for rural Appalachian families as they move along the illness trajectory at different rates. • Preserve generic/folk care that helps create a “sense of normalcy,” which provides support and comfort for living, even with life-limiting illness.
Culture Care Accommodation/Negotiation
• Accommodate faith practices among rural Appalachian families when making decisions at EOL. • Accommodate rural Appalachian economic diversity by assessing individual family resources, and developing a treatment and EOLC plan that fits the family’s cultural expressions, patterns, and practices. • Accommodate rural Appalachian families’ diverse hospice perspectives by creating community partnerships to co-develop train-the-trainer programs in which trusted community members teach others about EOLC options.
Culture Care Repatterning/Restructuring
• Repattern communication among families and interdisciplinary team members to facilitate family decision making at EOL by using easily-understood language and terminology, visual aids, and written materials that facilitate understanding of the life-limiting illness and EOLC choices. ○ An interdisciplinary team member must take responsibility to plant the seed by discussing the disease process and future EOLC needs with the family and interdisciplinary team members earlier in the illness trajectory. ○ All members of the interdisciplinary team are responsible for constantly reinforcing treatment options, EOLC options, and disease progression. ○ Negotiate with family to decide which family members to include in discussions, designating a family member who will be responsible for giving information to other family members, and including distant family members (suggest using technology such as Facetime, ZOOM, GoToMeeting, etc.) • Develop culturally congruent palliative care education for interdisciplinary providers in acute and community settings in order to help families understand EOLC options and make informed EOLC decisions.

Appendix B

Leininger's Sunrise Enabler



Source: McFarland, M. R. & Wehbe-Alamah, H. B. (2015). The theory of culture care diversity and universality. In M. R. McFarland and H. B. Wehbe-Alamah (Eds.), *Leininger's culture care diversity and universality: A worldwide nursing theory* (3rd ed., p. 25). Burlington, MA: Jones and Bartlett Learning.

Appendix C

Leininger's Stranger-to-Trusted-Friend Enabler

The purpose of this enabler is to facilitate the researcher (or it can be used by a clinician) to move from mainly a distrusted stranger to a trusted friend in order to obtain authentic, credible, and dependable data (or establish favorable relationships as a clinician); The user assesses him or herself by reflecting on the indicators as he/she moves from stranger to friend.

Indicators of Stranger (Largely <i>etic</i> or outsider's views)	Date Noted	Indicators as a Trusted Friend (Largely <i>emic</i> or insider's views)	Date Noted
Informant(s) or people are:		Informant(s) or people are:	
1. Active to protect self and others. They are "gatekeepers" and guard against outside intrusions. Suspicious and questioning.		1. Less active to protect self. More trusting of researchers (their "gatekeeping is down or less"). Less suspicious and less questioning of researcher.	
2. Actively watch and are attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.		2. Less watching the researcher's words and actions. More signs of trusting and accepting a new friend.	
3. Skeptical about the researcher's motives and work. May question how findings will be used by the researcher or stranger.		3. Less questioning of the researcher's motives, work, and behavior. Signs of working with and helping the researcher as a friend.	
4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values, and beliefs. Dislikes probing by the researcher or stranger.		4. Willing to share cultural secrets and private world information and experiences. Offers most local views, values, and interpretations spontaneously or without probes.	
5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.		5. Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time, and gives evidence of being a 'genuine friend.'	
6. Tends to offer inaccurate data. Modifies 'truths' to protect self, family, community, and cultural lifeways. <i>Emic</i> values, beliefs, and practices are not shared spontaneously.		6. Wants research 'truths' to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets <i>emic</i> ideas so researcher has accurate data.	

*Developed and used since 1959: Leininger.

Source: McFarland, M. R. & Wehbe-Alamah, H. B. (2015). Leininger's enablers for use with the ethnonursing research method. In M. R. McFarland and H. B. Wehbe-Alamah (Eds.), *Leininger's culture care diversity and universality: A worldwide nursing theory* (3rd ed., p. 78). Burlington, MA: Jones and Bartlett Learning. Used with permission (in the process of obtaining) Jones and Bartlett Learning.

Appendix D

Leininger's Observation-Participation-Reflection Enabler

Phases:	1	2	3	4
	Primary <i>Observation</i> and <i>Active Listening</i> (no active participation)	Primary <i>Observation</i> with limited participation	Primary <i>Participation</i> with continued observations	Primary <i>Reflection</i> and <i>Reconfirmation</i> of findings with informants

Source: McFarland, M. R. & Wehbe-Alamah, H. B. (2015). Leininger's enablers for use with the ethnonursing research method. In M. R. McFarland and H. B. Wehbe-Alamah (Eds.), *Leininger's culture care diversity and universality: A worldwide nursing theory* (3rd ed., p. 80). Burlington, MA: Jones and Bartlett Learning. Used with permission (in the process of obtaining) Jones and Bartlett Learning.

Appendix E1

Key Participant Recruitment Communication by Phone and Email

Sample Statements for Phone or Email to Recruit **Key Participants** (Rural Appalachians)

- My name is Mary Lou Clark Fornehed and I would like to invite you to consider being in a research study.
- I am a nurse and a PhD student at the University of Tennessee Knoxville College of Nursing. I am conducting a study to learn from you how nurses and other healthcare providers can help you and your family make decisions at end-of-life that are meaningful to you.
- Your participation is voluntary. Your decision to participate or not participate will NOT influence or impact your medical or nursing care.
- The study will involve observations of your environment and an interview. I would like to talk with you for 30–60 minutes at a place and time that is convenient for you.
- If you are willing to participate in an interview, please contact Mary Lou Clark Fornehed at mfornehe@vols.utk.edu or 931-607-2907.

IRB NUMBER: UTK IRB-16-03399-XP
IRB APPROVAL DATE: 01/23/2017

Appendix E2

General Participant Recruitment Communication by Phone and Email

Sample Statements for Phone or Email to Recruit **General Participants**
EOL, Palliative, and Acute Care Administrators, Hospice and Palliative Care Nurses, Case Managers, Social Workers, Rural Minister/Spiritual Counselors, Health Care Providers

- My name is Mary Lou Clark Fornehed and I would like to invite you to consider being in a research study.
- I am a nurse and a PhD student at the University of Tennessee Knoxville College of Nursing. I am conducting a study to learn from you how nurses and other healthcare providers can help you make meaningful decisions for your family member at end-of-life.
- Your participation is strictly voluntary. Your decision to participate or not participate will NOT influence or impact your employment.
- The study will involve observations of your environment and an interview. I would like to talk with you for 30–60 minutes at a place and time that is convenient for you.
- Your interview will be at a time and place convenient for you.
 - It will occur outside your scheduled work hours.
 - You may choose to be interviewed via telephone.
- If you are willing to participate in an interview, please contact Mary Lou Clark Fornehed at mfornehe@vols.utk.edu or 931-607-2907.

IRB NUMBER: UTK IRB-16-03399-XP
IRB APPROVAL DATE: 01/23/2017

Appendix F1

Recruitment Flyer for **Key Participants**

*As a person or family member from Rural Appalachia,
have you needed to make End of Life Care decisions?*

You are invited to participate in a research study where you may share your experiences in making decisions at end of life.

To participate you must be:

- 🌐 Age 40 years or older (patient) or 18 years or older (family)
- 🌐 *Patients* must have a life limiting illness with months, weeks, days, or hours to live.
- 🌐 Born and raised in Rural Appalachia
- 🌐 Be willing to share your views regarding end of life decision making
- 🌐 Speak and understand English
- 🌐 Be able to participate in a 30-60 minute interview

Participation is voluntary.

Risks: There are minimal risks to participants.

Benefits: Sharing information may help provide caregivers to assist others in making meaningful end of life care decisions.

Compensation: None

To learn more, contact the Principal Investigator, Mary Lou Clark Fornehed, Doctoral Candidate at 931-372-6808 or mfornehe@vols.utk.edu.
University of Tennessee Knoxville, College of Nursing

IRB NUMBER: UTK IRB-16-03399-XP
IRB APPROVAL DATE: 01/23/2017

Appendix F2

Recruitment Flyer for *General Participants*

As a Rural Appalachian health care provider, have you assisted a patient or their family to make meaningful End of Life Care decisions?

You are invited to participate in a research study about your experiences in providing this assistance.

To participate you must be:

- 🌐 Age 25 years or older
- 🌐 Be willing to share your views regarding end of life decision making
- 🌐 Speak and understand English
- 🌐 Be able to participate in a 30-60 minute interview

Participation is voluntary.

Risks: There are minimal risks to participants.

Benefits: Sharing information may help healthcare providers assist patients and families to make meaningful end of life care decisions.

Compensation: None

To learn more, contact the Principal Investigator, Mary Lou Clark Fornehed, Doctoral Candidate at 931-372-6808 or mfornehe@vols.utk.edu.
University of Tennessee Knoxville, College of Nursing

IRB NUMBER: UTK IRB-16-03399-XP
IRB APPROVAL DATE: 01/23/2017

Appendix G1

Informed Consent Statement

Rural Appalachian Person and Family Decision-Making at End-of-Life
University of Tennessee, Knoxville, College of Nursing

Key Informant

INTRODUCTION

You are asked to be a part of a research study. The goal of this study is to learn from you how nurses and other interdisciplinary healthcare providers can help you and your family make end of life care decisions that are meaningful to you.

INFORMATION ABOUT BEING IN THIS STUDY

You will be interviewed for this study. Interviews will be done when it is convenient for you and in a private place you choose such as your home, hospital, skilled nursing facility, hospice home, church, or community room such as a library or senior center. Observations of your environment will be conducted by the researcher immediately before and during interviews.

You will be asked for permission to audiotape the interview, and the researcher will take notes. You may also choose not to have your interview recorded; however, the researcher will still take notes. The interview will last about 30-60 minutes. The researcher will ask some questions, and you will be encouraged to talk about how your family makes decisions related to end of life care during a life-limiting illness.

At the end of the interview, the researcher will give you the chance to phone, email, or schedule another interview, if you would like. After the interview, you may think of more information you would like to share, and you may contact the researcher (contact information below).

The details you share will be kept private. The only people who will know your name are the researcher and her research advisor. The information you give us will be combined with other people's information, so you will not be singled out or identified. No one person will be known.

RISKS

There are minimal risks to take part in this study. They include:

1. Some sadness or distress during the interview
2. If this happens, the researcher will offer comfort, offer to stop the interview, and if necessary, encourage you to contact your healthcare provider.
3. Loss of confidentiality, as it is possible you could be linked to your data.

You can stop the interview at any time. If you become tired, ill, or unable to finish the interview for any reason, the interview will be stopped. You can then choose to

participate in another interview at a time convenient for you, or you can choose not to be interviewed any further.

The information you share while being interviewed will not contain your name or any other information that would identify you. Your interview information will be viewed by the

IRB NUMBER: UTK IRB-16-03399-XP

IRB APPROVAL DATE: 01/23/2017

IRB EXPIRATION DATE: 01/22/2018

researcher, her research advisor, dissertation committee, the professional transcriptionist, and possibly The University of Tennessee Institutional Review Board, which is responsible for protecting the rights and safety of research participants. These groups agree to keep your information private. However, complete confidentiality cannot be guaranteed.

BENEFITS

There are no direct benefits for participating in this study. The only potential benefit from your participation is that information you share may be useful for nurses and healthcare providers as they care for future people with life-limiting illness that have decision making needs in rural Appalachia. People who participated in a previous study were eager to share their stories, describing participation in positive terms such as leaving a legacy to help others.

CONFIDENTIALITY

A number will identify each participant's information. Some of the statements you share with the researcher will be used anonymously (without your name) in published research documents and at professional meetings. Informed consent and any paper files involving the participants will be scanned, digitized, and stored on password-protected computers behind the University of Tennessee, Knoxville (UTK) firewall using the Office of Research Administration Repository in Microsoft OneDrive, which is Health Insurance Portability and Accountability Act (HIPAA), Family Educational Rights and Privacy Act (FERPA), and Personally Identifiable Information (PII) certified storage. Paper files will be destroyed by shredding. All data will be stored for three years then destroyed by erasing all digital files or as per the recommendations of the CON Office of Research Administration.

COMPENSATION

There will be no payment to you for your participation in this study.

CONTACT INFORMATION

If there are questions at any time about the study or the interview, or if you experience adverse effects as a result of participating in this study, you may contact the researcher, Mary Lou Clark Fornehe at (931) 372-6808 (email: mfornehe@vols.utk.edu) or her advisor, Dr. Sandra Mixer at (865) 974-9430 (email: smixer@utk.edu). If you have

questions about your rights as a participant, you may contact the University of Tennessee IRB Compliance Officer at utkirb@utk.edu or (865) 974-7697.

PARTICIPATION

Your participation in this study is voluntary. You do not have to participate in the research. You may withdraw from the study at any time and Mary Lou Clark Fornehed will destroy any information that has already been collected through shredding of paper documents and erasure of digital audio files. Your decision to participate or not participate or to withdraw from the study does not have any effect on the care you and your family member receive.

IRB NUMBER: UTK IRB-16-03399-XP

IRB APPROVAL DATE: 01/23/2017

IRB EXPIRATION DATE: 01/22/2018

CONSENT TO PARTICIPATE

I have read the above information. I have received a copy of this form. I agree to take part in this study.

Participant's Name (printed)

Participant's Signature

Date

Investigator's signature

Date

CONSENT TO PARTICIPATE IN FUTURE RESEARCH

I have read the above information. I have received a copy of this form. I give permission to use this data for other secondary data sources.

Participant's Name (printed)

Participant's Signature

Date

Investigator's signature

Date

Appendix G2

Informed Consent Statement

Rural Appalachian Person and Family Decision-making at End-of-Life
University of Tennessee, Knoxville, College of Nursing

General Informant

INTRODUCTION

You are asked to be a part of a research study. The goal of this study is to learn from you how nurses and other interdisciplinary healthcare providers can help persons and their families make end of life care decisions that are meaningful to them.

INFORMATION ABOUT BEING IN THIS STUDY

You will be interviewed for this study. Interviews will be done when it is convenient for you and in a private place you choose such as a conference room in your healthcare facility or library. Observations of your environment will be conducted by the researcher immediately before and during interviews.

You will be asked for permission to audiotape the interview, and the researcher will take notes. Or you may choose not to have your interview recorded; however, the researcher will still take notes. The interview will last about 30-60 minutes. The researcher will ask some questions, and you will be encouraged to talk about your experiences helping families make decisions related to their care during a life-limiting illness.

At the end of the interview, the researcher will offer you the chance to phone, email, or schedule another interview, if you would like. After the interview, you may think of more information you would like to share, and you may contact the researcher (contact information below).

The details you share will be kept private. The only people who will know your name are the researcher and her research adviser. The information you give us will be combined with other people's information, so you will not be singled out or identified. No one person will be known.

RISKS

There are minimal risks to take part in this study. They include:

1. Some sadness or distress during the interview
2. If this happens, the researcher will offer comfort, offer to stop the interview, and if necessary, will encourage you to call your employee assistance program or your healthcare provider.
3. Loss of confidentiality, as it is possible you could be linked to your data.

You can stop the interview at any time. If you become tired, ill, or unable to complete the interview for any reason, the interview will be stopped. You can then choose to

participate in another interview at a time convenient for you, or you can choose not to be interviewed any further.

IRB NUMBER: UTK IRB-16-03399-XP

IRB APPROVAL DATE: 01/23/2017

IRB EXPIRATION DATE: 01/22/2018

The information you share while being interviewed will not contain your name or any other information that would identify you. Your interview information will be viewed by the researcher, her research advisor, dissertation committee, the professional transcriptionist, and possibly The University of Tennessee Institutional Review Board, which is responsible for protecting the rights and safety of research participants. These groups agree to keep your information private. However, complete confidentiality cannot be guaranteed.

BENEFITS

There are no direct benefits for participating in this study. The only potential benefit from your participation is that information you share may be useful for other nurses and healthcare providers as they care for future people with life-limiting illness.

CONFIDENTIALITY

A number will identify each participant's information. Some of the statements you share with the researcher will be used anonymously (without your name) in published research documents and at professional meetings. Informed consent and any paper files involving the participants will be scanned, digitized, and stored on password-protected computers behind the University of Tennessee, Knoxville (UTK) firewall using the Office of Research Administration Repository in Microsoft OneDrive, which is Health Insurance Portability and Accountability Act (HIPAA), Family Educational Rights and Privacy Act (FERPA), and Personally Identifiable Information (PII) certified storage. Paper files will be destroyed by shredding. All data will be stored for three years then destroyed by erasing all digital files or as per the recommendations of the CON Office of Research Administration.

COMPENSATION

There will be no payment to you for your participation in this study.

CONTACT INFORMATION

If there are questions at any time about the study or the procedures, or if you experience adverse effects as a result of participating in this study, you may contact the researcher, Mary Lou Clark Fornehed at (931) 372-6808 (email: mfornehe@vols.utk.edu) or her advisor, Dr. Sandra Mixer at (865) 974-9430 (email: smixer@utk.edu). If you have questions about your rights as a participant, you may contact the University of Tennessee IRB Compliance Officer at utkirb@utk.edu or (865) 974-7697.

PARTICIPATION

Your participation in this study is voluntary. You do not have to participate in the research. You may withdraw from the study at any time and Mary Lou Clark Fornehed will destroy any information that has already been collected through shredding of paper documents and erasure of digital audio files. Your decision to participate or not participate or to withdraw from the study will not have any effect on your work (either employment or in the community).

IRB NUMBER: UTK IRB-16-03399-XP

IRB APPROVAL DATE: 01/23/2017

IRB EXPIRATION DATE: 01/22/2018

CONSENT TO PARTICIPATE

I have read the above information. I have received a copy of this form. I agree to take part in this study.

Participant's Name (printed)

Participant's Signature

Date

Investigator's signature

Date

CONSENT TO PARTICIPATE IN FUTURE RESEARCH

I have read the above information. I have received a copy of this form. I give permission to use this data for other secondary data sources.

Participant's Name (printed)

Participant's Signature

Date

Investigator's signature

Date

Appendix H

Project Application

1.0 General Information	
* Please enter the full title of your study.
The UTHSC IRB (Memphis) may add to your title using brackets; please do not amend the information within the brackets.
For UT GSM (Knoxville) projects, include the generic/trade name of the HUD; the name of the device/drug for Treatment Use; the name of the device for Compassionate Use; or the name of the device/drug for Emergency Use.	
Rural Appalachian Person and Family Decision Making at End of Life	
* Please enter a working title up to 15 characters.	
Rural Appalachian Person and Family Decision Making at End of Life	
Working Title	
2.0 Add Department(s)	
2.1 * List all departments and affiliate institutions associated with this study/project, and always mark the Principal Investigator's UTHSC department as the primary department. If any of your study/project activities are being conducted at the following sites, list these organizations as well: Methodist and/or Le Bonheur, Regional One Health, Clinical Research Center (CRC), Office of Clinical Research, UTMG, Graduate School of Medicine, University Health System, University of Tennessee, Knoxville, Oak Ridge National Laboratories, University Family Physicians, UT Genetics Center, etc.
 For UTK projects, please select the PI's home department as the primary department for this study (alter if it is not pre-selected)	
Primary Dept?	Department Name
⊙	UTK - College of Nursing - Nursing
3.0 Assign key study/project personnel (KSP) access to the project	
3.1 * Please add a Principal Investigator for the project:	
Mary Lou Clark Fornehed	
Select if applicable	
☒ Student ☐ Department Chair ☐ Resident ☐ Fellow	
If the Principal Investigator is a Student, Resident, or Fellow, the name of the Faculty Advisor must be supplied below.	
3.2 If applicable, please select the Research Staff personnel (for UTK, collaborators from outside the institution should not be listed here):	
A) Additional Investigators	
Sandy Mixer, PhD, RN, CTN-A	
Co-Investigator	
B) Research Support Staff	
3.3 Please add a Project Contact:	
Mary Lou Clark Fornehed	
Sandy Mixer, PhD, RN, CTN-A	
The Project Contact(s) will receive all important system notifications along with the Principal Investigator. (The project contact(s) are typically the Study Coordinator(s) and the Principal Investigator).	

3.4 If applicable, please add a Faculty Advisor:
Sandy Mixer, PhD, RN, CTN-A
3.5 If applicable, please select the Designated Department Approval(s):
Diane Katherine Carr Other Lynda Hardy, PhD Department Chair Add the name of the individual authorized to approve and sign off on this protocol from your Department (e.g., the Department Review Chair, Dean, and/or Division Chief).
3.6 If applicable, please select the Research Administrative Specialist(s)
Diane Katherine Carr Lynda Hardy, PhD For UTHSC (Memphis) studies/projects: Add the appropriate Research Administrative Specialist if any of the following activities will occur at the institutions listed below: identification of subjects through review of their medical records; recruitment of subjects; consent of subjects; performance of screening procedures; interventions or interactions with subjects; follow-up visits; or collection of private information about subjects. If none of the activities described will occur at any of these locations, you do not need to complete this section of the application. - Methodist Healthcare - Memphis Hospitals - Rexann G. Pickering, PhD, RN - Le Bonheur Children's Hospital - Lisa Sentiff, MPH - Regional One Health/UT Regional One Physicians (UTROP) - Amira Wohabrebbi, PhD, BSN, RN In addition, add Vivian Loveless, Pharm.D. as a Research Administrative Specialist if your project will include exposure to X-rays and other machine-produced ionizing radiation solely for research purposes, non-FDA approved radioisotopes solely for research purposes, and/or FDA approved radioisotopes solely for research purposes. Lastly, if you have any dosimetry questions related to machine-produced ionizing radiation or radioisotopes used solely for research purposes, please contact Thad Wilson, Ph.D. at (901) 448-8323 or at tawilson@uthsc.edu. ===== For UT GSM (Knoxville) studies/projects: Completed, signed collaboration forms and/or approval letters are required at the time of IRB submission. If the research activity will utilize any resources of the following: Nursing Administration, Pathology, Pharmacy and/or Radiology, then please add the applicable Research Administrative Specialist(RAS) to your study: Nursing Admin-Suzanne Sawyer, MSN, RN, APN, ACNS-BC, RN-BC; Pathology-Amila Orucevic, MD, PhD; Pharmacy-Barbara Faircloth, PharmD, BCPS; Radiology-Dustin Osborne, PhD; Radiation Safety-Stephen Handley, MS.
4.0 (300) UTK IRB Submission
4.1 * Project Classification: Provide an appropriate description (e.g., Research Project, Dissertation, Thesis, etc.) NOTE: For ImedRIS submission assistance, please call (865) 974-7697. Revised 7/01/2016 ☐ Research Project ☐ Dissertation ☐ Thesis ☐ Undergraduate Honors Thesis ☐ Other
4.2 * Please indicate the correct status of this submission:
☐ I am requesting initial approval for research. ☐ I am registering research that was originally approved on paper by the UTK IRB. (Do not select this option unless instructed to do so by the IRB)

5.0 (415) UTK Key Project Study Contact Information

5.1 Please "add a new row" and provide the requested information below for all of the following individuals: Principal Investigator (listed in 3.1) All investigators and research support staff listed in 3.2 Project Contact listed in 3.3 (if not already included above) Faculty Advisor listed in 3.4 DO NOT include department approvers (3.5) or research admin specialists (3.6) Note: All iMedRIS correspondence will be sent automatically to your UT email account. You may contact the HELP Desk at (865) 974-9900 to have your UT email forwarded to another account.

Name	E-mail Address	Obtain Informed consent	Access to research records
Fornehed, Mary Lou Clark	mfomehe@utk.edu	Yes	☒ Yes ☐ No ☐ NA
Dr. Mixer, Sandy, PhD, RN, CTN-A	smixer@utk.edu	Yes	☒ Yes ☐ No ☐ NA

6.0 (417) UTK Key Study Personnel (KSP) Credentials

6.1 Please "add a new row" and provide the credentials and ROLES for all of the following individuals (Examples include John Smith, PhD-statistician; Mary Jones, graduate research assistant-recruitment) Principal Investigator (listed in 3.1) All investigators and research support staff listed in 3.2 Project Contact listed in 3.3 (if not already included above) Faculty Advisor listed in 3.4 Note: Investigators must specify their relevant qualifications and those of other investigators involved in this project to perform the proposed research. Include qualifications of personnel working on portions of the research where special training, certification, or licensing is required for the performance of their tasks. Experience and expertise is required when involving participants' classified as vulnerable, such as children, pregnant women, prisoners, cognitively impaired or institutionalized individuals.

KSP Name	KSP Credentials and Roles
Fornehed, Mary Lou Clark	I am the PI of this dissertation research project. I was the member of the research team in a rural Appalachian study, whose PI was my faculty advisor and committee chair, for which Culture Care Theory/Ethnonursing method was used. I have also lived and worked in rural Appalachia for more than 30 years. I am an Acute Care Nurse Practitioner who cares for patients at end of life. PI is working occasionally at Cookeville Regional Medical Center as an Acute Care Nurse Practitioner. PI will not be working in this role during data collection. My CitiTraining is complete.
Dr. Mixer, Sandy, PhD, RN, CTN-A	My research/theory mentor, nationally recognized as a Transcultural Nursing Scholar, Culture care theory, and ethnonursing research expert.

7.0 (420) Review Board Routing Questions

7.1 * Additional Research Compliance

* Select all of the following items that apply to this study.

- ☐ Exposure to X-rays and other machine-produced ionizing radiation solely for research purposes
- ☐ Radioactive Materials
- ☐ Potential Biological Hazards (viruses, recombinant DNA, etc.)
- ☐ Chemical Hazards (poisons, explosives, reagents, flammables, carcinogens, etc.)
- ☐ Research involves Animal Subjects
- ☐ A drug, device, and/or biologic is being administered and evaluated as part of the study/project procedures
- ☐ Collection of blood
- ☒ Not Applicable

8.0 (468) Funding Source
8.1 * Is there a funding source associated with the study/project?
☒ Yes ☐ No

9.0 (470) Funding Source						
9.1 Please designate your funding sources: Federal or Foreign Government; Sponsor Company; Medical Center or University; Not-for-Profit Organization						
	Sponsor Name	Sponsor Type	Funding Through	Contract Type:	Project Number	Award Number
	 Cookeville Regional Charitable Foundation	Not-for-Profit Organization				
Sponsor Name:		Cookeville Regional Charitable Foundation				
Sponsor Type:		Not-for-Profit Organization				
Funding Through						
Is Institution the Primary Grant Holder:		No				
Contract Type:						
Project Number						
Award Number						
Grant Title:						
Award Recipient:						
If Award Recipient is not the same as identified on the study.						
Explain Any Significant Discrepancy:						

10.0 (475) Contract Information
10.1 * Select the office or institution that is processing the grant or contract for this study/project. If there is no grant or contract for this study/project, enter "Not Applicable."
Other Please list the office or institution that is processing the grant or contract for this study/project: The UTK Office of Research Administration
10.2 Where is the project/proposal in the funding process?
☐ Not submitted (seeking IRB approval as first step) ☐ Submitted but not awarded ☒ Awarded
Is the proposal title different from this IRB project application? ☐ Yes ☒ No
List the following information (if applicable): Note: Please contact the office processing the contract/grant for the appropriate information. UTK - Evisions SP number or other Institution Log Number / Proposal Number Protocols for which the contract is handled by UTK Sponsored Programs require the Evisions SP number be entered here. If you have not yet routed the contract you may generate the Evisions SP number by filling out and saving the first page in Evisions SP. You will be assigned a Evisions SP number and may return to complete the routing when you are ready. Evisions SP#17-0948

Sponsor Award Number

Institution Award Number

Account Number

11.0 (485) Study/Project Information

11.1 * Are you requesting Full Board, Expedited or Exempt review by the IRB?

- ☐ Full Board
☒ Expedited
☐ Exempt
☐ Not Sure

12.0 (701) Define "Expedited" and Minimal Risk

12.1 "Expedited Review" is a speedier process than "Full Board Review." Proposals that may qualify for Expedited Review include: Research activities that 1) present no more than minimal risk to human participants AND 2) involve only procedures listed in one or more of seven Expedited Review Categories. By answering the following questions, you will assist the IRB in determining if your proposal will be granted an Expedited Review. Please hit "Save and continue..." in the upper right corner.

12.2 * Do the research activities present no more than minimal risk to human participants?

- ☒ Yes. The research activities present no more than minimal risk to human participants.
☐ No. The research activities DO present more than minimal risk to human participants.

12.3 * Would identification of the participants and/or identification of their responses reasonably place them at risk of criminal or civil liability or be damaging to the participants financial standing, employability, insurability, reputation, or be stigmatizing?

- ☐ Yes. Identification of participant or participant responses COULD place the participant at risk.
☒ No. Identification of participant or participant responses WOULD NOT place participant at risk.

12.4 Please indicate the Expedited category/ies that apply to your study:

- ☐ CATEGORY 1(B): Clinical studies of medical devices for which an investigational device exemption application is not required or the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
- ☐ CATEGORY 2: Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture (healthy non pregnant adults 110lbs or more, no more than 550mL in 8 weeks and no collection more than 2x a week OR other adults and children not exceeding the lesser of 50 ml or 3 ml per kg in an 8 week period and no collection more than 2x a week)
- ☐ CATEGORY 3: Prospective collection of biological specimens for research purposes by noninvasive means
- ☐ CATEGORY 4: Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing
- ☐ CATEGORY 5: Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as teaching, or internal evaluation, or medical treatment or diagnosis)
- ☒ CATEGORY 6: Collection of data from voice, video, digital, or image recordings made for research purposes
- ☒ CATEGORY 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

13.0 (925) Study/Project Synopsis

13.1 * Click on the bar below and provide a synopsis of the research study addressing the following FOUR items USING these numbered subheadings. Please be sure to provide enough detail that the IRB understands clearly what you propose to do, with whom, and why. Purpose/Objectives of the Study Study Population (including any inclusion/exclusion criteria) Study Procedures, and Planned Analyses

1. Purpose of the study:

The purpose of this qualitative ethnonursing study is to discover and describe the culture care expressions, patterns, and practices that influence rural Appalachian families when making decisions at EOL. The goal is to discover emic (generic/folk) and etic (professional) care that supports rural Appalachian families to make decisions that help them receive culturally congruent (CC) EOLC.

The following research questions will guide this qualitative study of rural Appalachian families engaging in decision making at end-of-life:

What are the culture care expressions, patterns, and practices that influence rural Appalachian families' decision making at EOL?

How do the worldviews, cultural and social structure, environmental context, and ethnohistory influence rural Appalachian family decision making at EOL?

What are the emic (generic) and etic (professional) care practices that influence rural Appalachian family decision making at EOL?

What culture care nursing actions would support rural Appalachian family decision making at EOL?

What culture care interdisciplinary team actions would support rural Appalachia family decision making at EOL?

2. Study population (including inclusion criteria):

Research enablers are used by the ethnonursing researcher to retrieve complex data and provide a relaxed and natural way for the informants to share their experiences (Wehbe-Alamah & McFarland, 2015a). The data to be used in this research study will come from interviews and field data gathered from key and general informants, using the research questions to explore the culture care expressions, patterns, and practices that influence rural Appalachian decision making at EOL.

Key and general informants will be recruited from within the 34 county area of eastern Tennessee in rural Appalachia. Some participants will be recruited from Cookeville Regional Medical Center, whose IRB has agreed to accept the IRB approval from the University of Tennessee, Knoxville (see Permission to Use UTK IRB).

The philosophic and epistemological sources of knowledge using the ethnonursing research method are "the people as the knowers about human care and other nursing knowledge" (Leininger, 2006, p. 52). Key informants/participants are people holding the most knowledge for answering the research questions. General informants/participants provide views of a wider population and important reflective data that further facilitate the researchers' understanding of person's meanings and experiences related to culturally congruent family decision making at EOL.

The number of participants recommended for ethnonursing research varies depending on whether the study is considered a mini- or maxi-level investigation. The number of participants can range from 6–12 key informants and 12–24 general informants (Wehbe-Alamah & McFarland, 2015a). While data saturation will be the main criteria for the number of study participants, it is anticipated 12 key informants and 24 general informants will be needed for data saturation to occur making this a maxi ethnonursing study.

Key informants will be adults 40 years of age or older with a life-limiting illness who have months, weeks, days, or hours to live and/or their adult family members (18 years of age or older). Informants must have been born and raised in rural Appalachia and be willing to share their views on family decision making at EOL. Informants will determine if they are willing and able to consent and participate in the study. 34-county area has a population that is 93%, white (non-Hispanic), English speaking persons therefore only participants who speak English will be included (U.S. Census Bureau, 2015). General informants will be healthcare providers and community leaders who are routinely involved with the study population. They will be adults over the age of 25. For example, general informants may be end-of-life, palliative, and acute care administrators/professional care providers; hospice and palliative care nurses; members of the interdisciplinary team; and rural ministers/spiritual counselors.

Appointments for interviews will be made at a time convenient for participants with flexibility to reschedule or stop the interview at any time to accommodate possible participant fatigue. Interviews will be conducted in a private place the participant chooses such as a skilled nursing facility, hospice home, church, conference room in a healthcare facility or library or community room such as at a senior center.

To recruit participants, the researcher will contact potential general informants within the east Tennessee region of rural Appalachia via phone or email (see Key and General Participant Recruitment Communications). Using the Snowballing technique, general informants will serve as gatekeepers for key informants. Revisions requested have been made with accommodation for patients who are dying and their families. Flyers/information sheets will be used by the general informants to provide information regarding the research study and PI contact information to potential participants. General informants will forward potential participants' name/contact information (at the request of the participant) to the PI. The researcher will contact and consent all key and general informants. Potential recruitment problems include difficulty identifying potential participants and study attrition due to death or dropout. Through her years as an Acute Care nurse practitioner in the area, the researcher has established trusting relationships with the necessary gatekeepers, which should aid recruitment. However, if initial recruitment is low, the researcher will seek other appropriate recruitment avenues such as faith communities and local organizations such as area Offices on Aging.

Data collection will consist of observations and individual interviews with participants after informed consent is obtained (see Key and General Participant Informed Consent). Observations will be conducted immediately before and during interviews. Observations about the environmental context, artifacts, nonverbal participant expressions, interview time and location, and researcher thoughts, feelings, and hunches will be recorded in a field journal. Information gathered will be digitally audiotaped, transcribed verbatim, and de-identified thru coding. The researcher anticipates interviews will last 30–60 minutes. The number of interviews to be conducted per participant will be 1-2 and will occur either in-person or via telephone. NVivo™ qualitative software package will be used to store data and facilitate data analysis.

3. Study procedures:

This is a qualitative ethnographic study using the theoretical framework of Culture Care Theory of Diversity and Universality. Ethnographic research method is a naturalistic and open discovery method that was designed to be used with Theory of Culture Care Diversity and Universality (Wehbe-Alamah & McFarland, 2015a). This method is ideal for facilitating the discovery of both emic (generic/folk) and etic (professional) perspectives related to rural Appalachian persons' cultural beliefs and lifeways during family decision making at EOL. This method will enable the researcher to respectfully enter the world of the rural Appalachian family as they make decisions about EOLC and gain knowledge about their largely unknown and complex emic expressions, patterns, and practices at EOL (Leininger, 1997; Wehbe-Alamah & McFarland, 2015a). Discoveries from this cultural group will facilitate the provision of culturally congruent nursing and interdisciplinary care for this unique population group.

4. Planned analysis: The data to be used in this research study will come from interviews and field data gathered from key and general informants, using research questions to explore the culture care expressions, patterns, and practices that influence rural Appalachian decision making at EOL.

The Sunrise Enabler (see attachment), Stranger-to-Trusted-Friend Enabler (see attachment), and the Observation-Participation-Reflection Enabler (see attachment) will be used to facilitate authentic and credible data from participants (Leininger, 2006; Wehbe-Alamah & McFarland, 2015b).

Data will be systematically analyzed using the four phases of ethnographic data analysis (see attachment) (Wehbe-Alamah & McFarland, 2015b). These phases will incorporate methodological rigor and guide the researcher to discover the culture care expressions, patterns, and practices embedded within field notes, observations, and interview data collected.

The data will be transcribed, and entered into NVivo™ qualitative computer software program. The Leininger-Templin-Thompson-Ethnographic Coding Enabler (see attachment) incorporates the domains of the culture care theory and will guide the coding structure for data analysis (Wehbe-Alamah & McFarland, 2015b). Data analysis begins the initial day of research and continues throughout the study.

14.0 (1075) Background & Current Status of Work in the Field

14.1 * Please provide a summary description of work in your field that should provide—to a lay audience—a scientific rationale for your study.

The dynamics of delivering care to persons at end of life (EOL) has dramatically changed in the last twenty years. Improved management of chronic illness and provision of aggressive life sustaining measures for an illness once deemed fatal are more common, increasing longevity significantly (National Institutes of Health [NIH], 2014; National Institute of Nursing Research [NINR], 2013). It is estimated that more than 40 million persons with life-limiting illness worldwide are candidates for some form of palliative or end-of-life care, however, less than 14% of them will receive it (World Health Organization [WHO], 2015).

The NIH (2004), in conjunction with the NINR (2013), supports research about end-of-life issues. IOM (2014) research and substantial evidence indicates family-oriented and patient-centered EOLC provides symptom relief for individuals with life-limiting illness and supports the quality of life of patients and their families. In order to provide supportive, culturally congruent care to dying rural Appalachian individuals and their families, the expressions, patterns and practices they use when making EOLC decisions must be discovered.

The Appalachian Mountains stretch more than 1000 miles along the eastern coast of the U.S. including 13 states from New York to Mississippi's Natchez Trace (MacAvoy & Lippman, 2001). Appalachian people have unique worldviews that define their cultural and social dimensions and traditions. Their values and beliefs include valuing strong social and family ties, self-reliance, pride, love of the mountains where they live, working hard, and maintaining strong moral values (Coyne, Demian-Popescu, & Friend, 2006; Lee, 2012; Mixer et al., 2014). Geographically, rural Appalachian people live in an impoverished and medically underserved area, with limited access to medical care (U.S. Department of Health and Human Services [USDHHS], 2016).

In the east Tennessee region of rural Appalachia, 34 counties are deemed medically underserved (USDHHS, 2016b) and health provider shortage areas (USDHHS, 2016a). Poverty is widespread in this area, with approximately 21 % of rural Appalachians in these counties being at or below poverty level, as compared to 17.6 % of Tennessee residents and 15.4% nationwide (Appalachian Regional Commission, 2013; U.S. Census Bureau, 2015). Several factors—limited education, diminished health literacy, and rural and mountainous geographic

terrain—make it difficult for this vulnerable population to access EOLC services (Bakitas, Clifford, Dionne-Odom, & Kvale, 2015; Carlson, Bradley, Du, & Morrison, 2010; Coyne et al., 2006; Mixer et al., 2014).

Rural Appalachians in eastern Tennessee have the basic human right to seek and receive EOLC, as set forth by the United Nations (2011) in the Universal Declaration of Human Rights. The EOLC care they receive should be informed by their cultural expressions, patterns, and practices. For example, Lee (2012) studied Appalachian women and children who were living in a homeless shelter. Her study, guided by the CCT and ethnographic method, viewed this vulnerable and marginalized population through the emic lens and examined the meanings and experiences of family homelessness and its influence on health. She discovered that, while respectful care was vital to these families, they faced many cultural challenges and frequently felt disrespected.

The rural Appalachian honors the family unit, with many decisions regarding health and EOLC made as a family unit (Brown & May, 2005; Mixer et al., 2014). When patients and families must cope with life-limiting illness, the decision to begin EOLC is often the most difficult one they make (Wallace, 2015a). While family roles for day-to-day decision making may be well defined, formal family roles generally are not culturally defined in any population. Quinn and colleagues used ethnography to describe family members' informal roles when EOLC decision making was initiated in the intensive care unit. They found many informal roles evolved during the decision-making process. Researchers concluded that it is necessary for healthcare providers to employ strategies that accommodate these informal roles to facilitate family decision making and ensure a smooth transition to EOLC.

While evidence supports the important role of family decision making in the rural Appalachian culture when addressing life-limiting illness, there is little known regarding the culture care needs of the family when making EOLC decisions. Guided by the CCT, the findings from this study will contribute to the discipline of nursing by providing a better understanding of the culture care expressions, patterns, and practices and care actions that promote culturally congruent decision making for EOLC.

This study has significance for rural Appalachian families at EOL due to increasing number of persons in this population who will need EOLC in a medical culture that focuses on extending life as reflected in trends of increased ICU admissions and aggressive treatment of life-limiting illnesses (NIH, 2014; NINR, 2013; Schreiber-Baum et al., 2016). Several factors result in rural Appalachian persons having limited access to comprehensive palliative and hospice services including a lack of EOL-educated healthcare providers and geographically remote persons with low healthcare literacy (Bakitas et al., 2015; Campbell, Merwin, & Yan, 2009; Carlson et al., 2010; Coyne et al., 2006; Mixer et al., 2014; Robinson et al., 2009; Schreiber-Baum et al., 2016). Teno et al. (2013) reported that, despite conflicting literature from the National Center for Health Statistics (2010) that more persons are dying at home, nationwide more persons are being admitted to an ICU prior to death, being hospitalized 90 days prior to death, and transitioning to home or a skilled nursing facility meant an average of 3 days or less of EOLC in 2009. These factors resulted in the population spending an average of three days or fewer in EOLC in 2009. The National Hospice and Palliative Care Organization (2015) reported that dying patients spent an average of seven days or less in hospice care in 2014. While persons with life-limiting illness and their families may have viewed those few days at home as beneficial in terms of symptom management, and emotional, spiritual, and bereavement support, it is not known what the family or caregiver experienced when making care decisions, if persons' culture was acknowledged, if their care was planned to meet their needs at EOL, or if they were given dignity in death (Campbell et al., 2009; Lynch, 2013; Riffin et al., 2015; Schreiber-Baum et al., 2016). EOLC, such as hospice care, can be delivered at home, in an acute care setting, or in a long-term care facility. In 2013, The Medicare Payment Advisory Commission (2015) reported that only 26% of hospice care units were located in rural areas. This fact presents many challenges for this population including having a lack of family members to care for a dying person at home, needing to travel long distances for care, and experiencing difficulty with Medicare reimbursement.

This study has significance for EOLC clinicians because most are unfamiliar with the type of services rural Appalachians need at EOL and lack the practical and cultural EOLC knowledge need to care for these patients (Lynch, 2013; Schreiber-Baum et al., 2016). There is no known research about how persons in rural Appalachia and their families make decisions at EOL, either as a family unit or in conjunction with an interdisciplinary EOLC team. The literature does indicate there are poor communication and a lack of shared decision making between the family and interdisciplinary care team that can lead to the provision of unwanted, aggressive elder care in ICUs instead of EOLC (Dillworth et al., 2016; Heyland et al., 2015). With physicians generally serving as the gatekeepers for hospice services, and Appalachia being an underserved healthcare provider area (USDHHS, 2016b; Wallace, 2015b), there may not be enough physicians in the area to refer these patients to appropriate EOLC (Campbell et al., 2009). Culture and ethnicity is perhaps the leading determination of how persons and families view EOLC. Generally, Western culture sees EOLC decision making as a process performed by autonomous individuals who are focused on their quality of life (Coyle, 2014; Lynch, 2013). Culturally, rural Appalachians often maintain that families be included in all decisions when a person has a life-limiting illness. It is important that clinicians recognize these differences when discussing palliative care with these patients and their families. While there was no known quantitative research to predict rural Appalachian utilization of palliative care services, such as hospice care, research findings have shown a disparity in rural Appalachians' use of these services compared with other minorities. It is possible that rural Appalachians do not readily access hospice care because of their cultural beliefs (such as their distrust of strangers and strong spiritual beliefs) and a lack of referrals from a physician pool with deficient cultural knowledge about rural Appalachia (Lynch, 2013).

This study has significance for EOLC policy because such policy needs to be changed to reflect the fact that, in general, the rural Appalachian population has significant healthcare illiteracy and is uninformed regarding palliative care options (Schreiber-Baum et al., 2016). A major knowledge barrier cited in the literature was the interchangeable use of EOL terminology; with most persons believing that hospice care is focused on dying rather than living, thus limiting the demand for these services. Robinson et al. (2009) refers to the care providers in rural

areas as generalist professionals with palliative care being provided to only a miniscule portion of their patient population. The extremely limited use of palliative care in this region has made it difficult for providers to focus on the constantly changing knowledge and skills needed to help persons and their families make decisions at EOL. Medicare restricts hospice care access for patients who chose to continue curative care for life-limiting illnesses, thus limiting the palliative care options available to these patients (Wallace, 2015b) such as palliative radiation, chemotherapy, and intravenous nutrition. Rural Appalachian persons and their families frequently continue aggressive curative care since stopping these therapies, even at EOL, is seen as giving up and losing faith in God's curative nature (Behringer & Krishnan, 2011; Shell & Tudiver, 2004). With such restrictive hospice care policies, many rural Appalachians unable to access palliative care experience poor symptom control, more hospitalizations, and poor quality of life. In contrast to the current care model, two counties included in this study (Hamblen and Knox) are participating in a new care initiative that is testing a payment and service delivery model called the Medicare Care Choices Model (Centers for Medicare & Medicaid Services, 2016b). This pilot care model is evaluating the quality of life, care received, and costs incurred by Medicare and Medicaid recipients in 140 U.S. cities. The program is testing the idea that providing curative care in conjunction with hospice-like support to these persons and their families will result in improved quality of life and reduced Medicare costs.

This study has significance to EOLC economics because not only is providing the wrong type of care (aggressive, curative care when palliative/hospice/EOLC is more appropriate) detrimental to patients it is not cost effective. The current healthcare system structure fails to incentivize proactive and coordinated care for persons with life-limiting illness and their families, resulting in barriers that prevent patients from obtaining the right care at the right time (Schreibers-Baum et al., 2016). In any population, the gold standard for palliative care is a patient-centered, culturally appropriate plan made by an interdisciplinary team that includes and supports the family. Such plans decrease the use of inpatient healthcare services by persons with life-limiting illness (Bainbridge, Seow, & Sussman, 2016; Bekelman et al., 2016; Colaberdino, Marshall, DuBose, & Daitz, 2016; Robinson et al., 2009). Achieving this gold standard is not common in rural settings that have limited access to interdisciplinary palliative care teams. For providers to be reimbursed for hospice care, the ill person must be deemed as having six months or less to live and forgo curative treatment. If rural Appalachians chose to forego their hospice benefit, there are few options for appropriate EOLC that support both person and family, leading to a significant economic burden for those who wish to die at home (Essue et al., 2015; Robinson et al., 2009). Because of these reimbursement problems, hospice consults often are made late in the dying process (Lynch, 2013), resulting in increased ICU admissions and the continued provision of aggressive curative treatment in the last days of life, which leads to higher EOLC costs (Garrido, Prigerson, Bao, & Maciejewski, 2016), shortened hospice stays, and a large gap in EOLC services (Teno et al., 2013). In fiscal year 2017, the Centers for Medicaid & Medicare will begin new quality measures for Medicare-certified hospice centers (Centers for Medicare & Medicaid Services, 2016a). Two of these measures address the treatment preferences, beliefs, and values desired by the dying person and their family. If these quality measures are not met, there will be a 2% reduction in Medicare payment to the hospice provider. The knowledge discovered in this study could help inform hospice care providers of the cultural values and beliefs used in family decision making regarding EOL treatment in rural Appalachia.

15.0 (1200) Site Information

15.1 * Please list all sites where the study will occur, and list the procedures that will take place at each site.

To recruit participants, the researcher will contact potential general informants within the east Tennessee region of rural Appalachia via phone or email (see attachments for Key and General Participant Recruitment Communications). Using the Snowballing technique, general informants will serve as gatekeepers for key informants. The researcher will contact all key and general informants. Upon meeting them at a time and place convenient for (as described above), informants will be consented. General informants will help identify other informants from their acquaintances and report these possible participants to the nurse researcher. Potential recruitment problems include difficulty identifying potential participants and study attrition due to death or dropout. Through her years as an Acute Care nurse practitioner in the area, the researcher has established trusting relationships with the necessary gatekeepers, which should aid recruitment. However, if initial recruitment is low, the researcher will seek other appropriate recruitment avenues such as faith communities and local organizations such as area Offices on Aging. These interviews with key participants will occur at a time and private place that is convenient for the participant (ie...home, place of worship, or Cookeville Regional Medical Center). Interviews for general informants will occur at a time and private place convenient for them as well. This could include home, place of worship, or Cookeville Regional Medical Center.

Describe the research setting (e.g. classroom, clinic, laboratory, office, park, personal computer).

Key and general informants will be recruited from within the 34 county area of eastern rural Appalachia. Some participants will be recruited from Cookeville Regional Medical Center, whose IRB has agreed to accept the IRB approval from the University of Tennessee, Knoxville (see attachment for letter regarding IRB approval from Cookeville Regional Medical Center).

Data collection will consist of observations and individual interviews with participants after informed consent is obtained (see attachments for Key and General Participant Informed Consent). Observations about the environmental context, artifacts, nonverbal participant expressions, interview time and location, and researcher thoughts, feelings, and hunches will be recorded in a field journal. Information gathered will be digitally audiotaped, transcribed verbatim, and de-identified thru coding. The researcher anticipates interviews will last 30–60 minutes. NVivo™ qualitative software package will be used to store data and facilitate data analysis.

15.2 * Are any of the locations listed above non-UTK facilities? If a project is to be conducted at, or in collaboration with, another university and/or a medical facility, documentation of IRB approval from the other institution must be submitted. If a project is to be conducted at, or in collaboration with, a school, agency, business, organization, etc., an official letter of support from the institution must be submitted.

☐ Yes ☐ No

What is the status of the other facility's review?

- ☐ Future plans
☐ In process
☒ Ready to process

16.0 (1400) Participant Population

16.1 Number of participants to be accrued by UTK investigators. [This is the total number of participants you expect to consent. For retrospective review of records, include the total number of files you will have access to.]

* Number of participants to be accrued by UTK investigators. [This is the total number of participants you expect to consent. For retrospective review of records, include the total number of files you will have access to.]

36

* Age range of participants:

Key persons 40 years/family >=18 years; General persons >= 25 years

Is any racial/ethnic group excluded?

- ☐ Yes
☒ No

Provide an explanation if any racial/ethnic group is excluded.

17.0 (1488) Vulnerable Participants

17.1 * Will the study include any of the following populations, either as participants enrolled into the study or about whom data or specimens are used in the research? Select ALL that apply, for example, if the study investigates elementary students, select both Students and Children (under age 18).

- ☐ Students
☐ Children (under age 18)
☐ Children (under age 18) Who are Wards of the State
☐ Individuals Who Have a Pre-Existing Relationship with Investigator (e.g., investigator's own students, employees, advisor/advisee, clients, patients, subordinates)
☐ Employees
☐ Non-English Speakers
☐ Individuals with Limited Literacy or Whose Primary Language is Not English
☐ International Populations
☐ Individuals with Impaired Decision-Making Capacity
☐ Individuals on Probation, Parole, or Restricted by Court Order (e.g., court-ordered class attendance or community service)
☐ Prisoners, Detainees or Participants in an Alternative Sentencing/Diversion Program
☐ Pregnant Women
☐ Other, describe in text box below
☒ None of the above

18.0 (1490) FERPA

18.1 * In order to conduct this research, or to identify or recruit potential participants, are you requesting to use documents or materials that contain information protected under the Family Educational Rights & Privacy Act (FERPA) without obtaining the permission of the participants?

☐ Yes

☒ No

19.0 (1494) Study/Project Duration

19.1 * What is the anticipated duration of a single participant's participation in the study/project? The information you provide in this section should match the information you provide in the consent form.

The interview will last about 30-60 minutes. The researcher will ask some questions, and you will be encouraged to talk about how your family makes decisions related to care during a life-limiting illness. At the end of the interview, the researcher will offer you the chance to phone, email, or schedule another interview, if you desire. After the interview, you may think of more information you would like to share, and you may contact the researcher.

20.0 (1600) Participant Recruitment

20.1 * Please explain in detail all procedures you will use to recruit participants into your study.

The philosophic and epistemological sources of knowledge using the ethnonursing research method are "the people as the knowers about human care and other nursing knowledge" (Leininger, 2006, p. 52). Key informants/participants are people holding the most knowledge for answering the research questions. General informants/participants provide views of a wider population and important reflective data that further facilitate the researchers' understanding of person's meanings and experiences related to culturally congruent family decision making at EOL. Key informants will be adults 40 years of age or older with a life-limiting illness who have months, weeks, days, or hours to live and/or their adult family members (18 years of age or older). Informants must have been born and raised in rural Appalachia and be willing to share their views on family decision making at EOL. The 34-county area has a population that is 93% white (non-Hispanic), English speaking persons therefore only participants who speak English will be included (U.S. Census Bureau, 2015). General informants will be healthcare providers and community leaders who are routinely involved with the study population. They will be adults over the age of 25. For example, general informants may be end-of-life, palliative, and acute care administrators/professional care providers; hospice and palliative care nurses; members of the interdisciplinary team; and rural ministers/spiritual counselors.

To recruit participants, the researcher will contact potential general informants within the east Tennessee region of rural Appalachia via phone or email (see General Participant Recruitment Communications). Using the Snowballing technique, general informants will serve as gatekeepers for key informants. Revisions requested have been made with accommodation for patients who are dying and their families. Flyers/information sheets will be used by the general informants to provide information regarding the research study and PI contact information to potential participants. General informants will forward potential participants' name/contact information (at the request of the participant) to the PI. The researcher will contact and consent all key and general informants. Potential recruitment problems include difficulty identifying potential participants and study attrition due to death or dropout. Through her years as an Acute Care nurse practitioner in the area, the researcher has established trusting relationships with the necessary gatekeepers, which should aid recruitment. However, if initial recruitment is low, the researcher will seek other appropriate recruitment avenues such as faith communities and local organizations such as area Offices on Aging.

20.2 Recruitment Materials At the end of this application, you are required to attach all recruitment materials which you intend to use for this study/project.

21.0 (2000) Risks & Benefits

21.1 * Describe the possible risks to participants (including psychological harm, economic harm, social stigmatization, legal harm and physical harm if applicable). Include justification of those known risks.

The goal of this ethnonursing research study is to discover the culture care expressions, patterns, and practices of rural Appalachian persons making decisions at EOL, in order to produce information that could be used to improve care for patients and their family caregivers. EOLC studies are challenging because death is a sensitive subject, dying persons and their families are considered vulnerable populations, and the methodology is likely to uncover deeply personal expressions, patterns, and practices at EOL that must be handled sensitively to prevent burnout (Ferrell, Grant, & Sun, 2015; Henry & Scales, 2012; Kavanaugh & Campbell, 2014). The researcher is an expert nurse, practitioner, and educator in EOL and EOLC and will be sensitive to all participants in the study.

18.1 * In order to conduct this research, or to identify or recruit potential participants, are you requesting to use documents or materials that contain information protected under the Family Educational Rights & Privacy Act (FERPA) without obtaining the permission of the participants?

☐ Yes

☒ No

19.0 (1494) Study/Project Duration

19.1 * What is the anticipated duration of a single participant's participation in the study/project? The information you provide in this section should match the information you provide in the consent form.

The interview will last about 30-60 minutes. The researcher will ask some questions, and you will be encouraged to talk about how your family makes decisions related to care during a life-limiting illness. At the end of the interview, the researcher will offer you the chance to phone, email, or schedule another interview, if you desire. After the interview, you may think of more information you would like to share, and you may contact the researcher.

20.0 (1600) Participant Recruitment

20.1 * Please explain in detail all procedures you will use to recruit participants into your study.

The philosophic and epistemological sources of knowledge using the ethnonursing research method are "the people as the knowers about human care and other nursing knowledge" (Leininger, 2006, p. 52). Key informants/participants are people holding the most knowledge for answering the research questions. General informants/participants provide views of a wider population and important reflective data that further facilitate the researchers' understanding of person's meanings and experiences related to culturally congruent family decision making at EOL. Key informants will be adults 40 years of age or older with a life-limiting illness who have months, weeks, days, or hours to live and/or their adult family members (18 years of age or older). Informants must have been born and raised in rural Appalachia and be willing to share their views on family decision making at EOL. The 34-county area has a population that is 93% white (non-Hispanic), English speaking persons therefore only participants who speak English will be included (U.S. Census Bureau, 2015). General informants will be healthcare providers and community leaders who are routinely involved with the study population. They will be adults over the age of 25. For example, general informants may be end-of-life, palliative, and acute care administrators/professional care providers; hospice and palliative care nurses; members of the interdisciplinary team; and rural ministers/spiritual counselors.

To recruit participants, the researcher will contact potential general informants within the east Tennessee region of rural Appalachia via phone or email (see General Participant Recruitment Communications). Using the Snowballing technique, general informants will serve as gatekeepers for key informants. Revisions requested have been made with accommodation for patients who are dying and their families. Flyers/information sheets will be used by the general informants to provide information regarding the research study and PI contact information to potential participants. General informants will forward potential participants' name/contact information (at the request of the participant) to the PI. The researcher will contact and consent all key and general informants. Potential recruitment problems include difficulty identifying potential participants and study attrition due to death or dropout. Through her years as an Acute Care nurse practitioner in the area, the researcher has established trusting relationships with the necessary gatekeepers, which should aid recruitment. However, if initial recruitment is low, the researcher will seek other appropriate recruitment avenues such as faith communities and local organizations such as area Offices on Aging.

20.2 Recruitment Materials At the end of this application, you are required to attach all recruitment materials which you intend to use for this study/project.

21.0 (2000) Risks & Benefits

21.1 * Describe the possible risks to participants (including psychological harm, economic harm, social stigmatization, legal harm and physical harm if applicable). Include justification of those known risks.

The goal of this ethnonursing research study is to discover the culture care expressions, patterns, and practices of rural Appalachian persons making decisions at EOL, in order to produce information that could be used to improve care for patients and their family caregivers. EOLC studies are challenging because death is a sensitive subject, dying persons and their families are considered vulnerable populations, and the methodology is likely to uncover deeply personal expressions, patterns, and practices at EOL that must be handled sensitively to prevent burnout (Ferrell, Grant, & Sun, 2015; Henry & Scales, 2012; Kavanaugh & Campbell, 2014). The researcher is an expert nurse, practitioner, and educator in EOL and EOLC and will be sensitive to all participants in the study.

Potential risks of participating in this ethnonursing research study include emotional distress due to the sensitive nature of the questions that will be asked during the interview and participant fatigue and subsequent participant burden related to lengthy interviews. A loss of confidentiality is a possible risk related to this research. It is possible participants could be linked to their data or their association with the study. Even when safeguards are used to minimize the likelihood of a unintentional disclosure, such a disclosure is still a risk associated with the study.

21.2 Describe ways in which this risk, if any, will be minimized.

Care will be taken to mitigate or lessen these potential risks. The researcher will begin by accessing and recruiting key participants who have received a palliative care consultation. As an expert in EOLC, the researcher is consulted by her colleagues, allowing her to access potential participants through these gatekeepers. The study will be introduced to gatekeepers, including any interdisciplinary team members that may be asked to participate as general informants (as described above). Clear, broad, inclusion criteria have been set in order to maximize participant recruitment. Interview questions (see attachments for Key and General Participant Interview Guides) will use sensitive language that can communicate with the rural Appalachian participant in a way they can easily understand. Appointments for interviews will be made at a time convenient for participants with flexibility to reschedule or stop the interview at any time to accommodate possible participant fatigue.

It is well documented that repeated exposure to environments where there is the constant need to help someone who is suffering and dying leads to difficulty in providing services to this patient population and eventual burnout (Abendroth & Flannery, 2006; Santiago & Abdool, 2011; Vanderspank-Wright, Fothergill-Bourbonnais, Malone-Tucker, & Silvar, 2011; Wiegand & Funk, 2012). Since the researcher will be the primary data collector, self-care strategies will be in place to mitigate this type of stress. Strategies might include journaling, exercising, peer and mentor support, and limiting the number of interviews conducted in any given period. These strategies will enable the researcher to be present as an open, active listener, who is able to express empathy and caring (Kavanaugh & Campbell, 2014).

21.3 Is there potential for direct benefit to the participant?

☐ Yes ☒ No

21.4 Will there be benefit to the class of participants?

☐ Yes
☒ No

21.5 * Please describe the potential societal/scientific benefit of this research. (Also, if you selected "yes" to either of the last two questions, please describe the potential direct benefit to participants and/or to the class of participants.)

The findings of the study will guide nurses and other interdisciplinary caregivers as they assist rural Appalachian families in making decisions that are meaningful and beneficial to them at EOL. See background and significance for family, provider, policy, and economic benefits.

22.0 (2800) Confidentiality 1

22.1 * Please specify how all paper research records containing data from individual participants, or information about them (such as informed consent forms) will be locked and stored and accessible only to research personnel. Type "n/a" if not applicable to the study.

The data set transcripts collected from this study will be uploaded to NVivo™ qualitative research software to be stored and analyzed. Hard copies of any files involving the participants, after being digitized, will be shredded. Digitized copies will be stored 1) separate from other research documents, 2) in PDF format in a password protected folder, and 3) in the Office of Research Administration Repository protected by the UTK firewall.

Participants will be identified through a predetermined coding algorithm. Participants will be coded using (G) for general informant and (K) for key informant and then a number assigned as data is collected; i.e. G1, G2, K1, K2..etc; The link between the participant and the codes will only be on the informed consent. The identification of participant information and participant identification code (PID) will be kept in a separate password protected file.

22.2 * Please specify how all electronic research records containing data from individual participants will be computer password protected and accessible only to research personnel. (You may find it useful to consult

<http://help.utk.edu/kb/index2.php?func=show&e=2483> for secure file storage and transmission options.) Type "n/a" if not applicable to the study.

Hard copies, after being digitized, will be shredded. Digitized copies will be stored 1) separate from other research documents, 2) in PDF format in a password protected folder, and 3) in the Office of Research Administration Repository protected by the UTK firewall.

Access to study documents stored in the ORA Repository will be restricted to the principal investigator and their designee. The ORA Repository Administrator has restricted access to repository contents solely for the protection of the site and data. The data will be stored for a period of three (3) years after the close of the study.

Digital audio recordings from the field will be transferred from the researchers digital recorder to the Office of Research Administration Repository immediately after the interview has been concluded then deleted from the digital recorder. Once transcribed, these hard-copy transcripts will be digitized into PDF format and stored in a password protected folder, separate from other research documents, and in the Office of Research Administration Repository protected by the UTK firewall.

22.3 * Please specify how all biological specimens from individual participants maintained at the local investigative site will be labeled with a code (i.e., identifying information such as name or SSN will be replaced with a number, letter, symbol, etc.). Your description should include the coding procedures as well as who will have access to the code key, and where it will be stored. Type "n/a" if not applicable to the study.

"n/a"

22.4 * Please specify the secure transmission procedures for any research records containing data on individual participants, or any specimens from individual participants, that will be transmitted/shipped to an external site (this includes emailing data to yourself or another party). Your description should include any coding procedures that will be used, as well as who will have access to the code key, and where it will be stored. (You may find it useful to consult <http://help.utk.edu/kb/index2.php?func=show&e=2483> for secure file storage and transmission options.) Type "n/a" if not applicable to the study.

"n/a"

23.0 (3045) Payment

23.1 * Will any type of payment (money, gift card, course credit or other item) be provided to the participant for participation?

☐ Yes ☒ No

24.0 (3300) Conflict of Interest

24.1 * Do you, any of your study personnel, or any of their immediate families, have any conflicts of interest related to conducting this research project? (Please review the UT COI policy for additional details: http://policy.tennessee.edu/fiscal_policy/fi0125/)

☐ Yes
☒ No

24.2 * Do any individuals among the key research personnel (including their spouses, parents, and children) have intellectual property rights (patents, trademarks, or copyrights) in the entity being evaluated in the research and received income related to such rights and interests?

☐ Yes. Key study personnel or their spouses, parents, or children do have intellectual property rights related to the entity being evaluated and received income related to such rights and interests.
☒ No. Key study personnel (or their spouses, parents, or children) do not have intellectual property rights related to the entity being evaluated.
☐ Not Applicable.

25.0 (3329) Informed Consent

25.1 * Check each of the following that apply to your study/project:

- ☒ Informed consent will be secured from adult participants who are able to consent for themselves.
- ☐ Informed consent will be secured from legally authorized representatives for adult participants who are not able to consent for themselves.
- ☐ Permission will be secured from legally authorized representatives for children who are participants.
- ☐ Assent will be secured from children 7 years of age and older who are participants.
- ☐ A request is being made to WAIVE consent for some or all participants. (Note: If you select this option, you will be prompted to respond to specific prompts that will allow the IRB to determine if you qualify for a waiver of consent.)
- ☐ A request is being made to ALTER consent for some or all participants, e.g., consent will be obtained, but signed consent forms will not be maintained. (Note: If you select this option, you will be prompted to respond to specific prompts that will allow the IRB to determine if you qualify for an alteration of consent.)
- ☐ Non-English speaking participants will be included in the study population.

26.0 (3440) Consent Process

26.1 * Briefly explain when and where informed consent, permission and/or assent will be sought.

Informed consent will be secured from adult participants who are able to consent for themselves. Participants will determine if they are willing and able to consent and participate in the study. Additionally, the PI, as an Acute Care Nurse Practitioner with 31 years of nursing experience, will use her clinical judgment. The researcher routinely assists patients with life limiting illnesses complete informed consent for medical procedures. Those persons at end-of-life and their families who consent and participate in research will have adequate decision-making capacity. Decision making capacity refers to the participants' ability to understand the research information provided to them and come to a conclusion regarding their participation that makes sense to them. This researcher understands that persons at end-of-life may be cognitively impaired, however the literature substantiates that when end-of-life research involves only interviews and observations that pose minimal risks, informal capacity assessments are sufficient to determine decision-making capacity at that moment of interview and observation by the researcher (Casarett, 2005; Casarett & Karlawish, 2000; Henry & Scales, 2012). These informal assessments are used on a daily basis by the researcher as an Acute Care Nurse Practitioner in order to determine patient decision-making capacity for many procedures. An informal capacity assessment would consist of evaluating level of consciousness (is the participant awake and alert), are symptoms and pain controlled, and is the participant oriented to person, place, and time (including the day, month, year, and season). The participant will be excluded from the study if they cannot pass this informal capacity assessment. It should also be noted that the assessment would be ongoing, as cognitive impairment can occur at any time during the end-of-life process. The participants will be asked for permission to audiotape the interview, and the researcher will take notes. Or they may choose not to have their interview recorded; however, the researcher will still take notes. The interview will last about 30-60 minutes. The researcher will ask some questions, and the participant will be encouraged to talk about how their family makes decisions related to care during a life-limiting illness or be encouraged to talk about their experiences helping families make decisions related to their care during a life-limiting illness. At the end of the interview, the researcher will offer them the chance to phone, email, or schedule another interview, if they desire. After the interview, the participant may think of more information they would like to share, and may contact the researcher at the number provided on the consent form.

Casarett, D. (2005). Ethical considerations in end of life care and research. *J Palliat Med*, 8(Supplement 1), S148-S160.

Casarett, D. J., & Karlawish, J. H. (2000). Are special ethical guidelines needed for palliative care research? *J Pain Symptom Manage*, 20(2), 130-139.

Henry, B., & Scales, D. C. (2012). Ethical Challenges in Conducting Research on Dying Patients and Those at High Risk of Dying. *Accountability in Research-Policies and Quality Assurance*, 19(1), 1-12.
doi:10.1080/08989621.2011.622173

27.0 (3450) Protected Health Information (PHI)

27.1 * In order to conduct this research, or to identify or recruit potential participants, are you requesting to use SOURCE DOCUMENTS or SOURCE MATERIALS that contain the Protected Health Information of persons without their authorization (or with their limited authorization) AND/OR are you obtaining Protected Health Information of persons without their authorization (or with their limited authorization), such as through telephone screening? Note: Source documents/materials are documents/materials from which you are going to abstract information in order to conduct this research or to identify or recruit potential participants, for example, a patient's medical record.

☒ Yes. I am requesting to use source documents/materials that contain Protected Health Information (PHI) of persons (living or dead) without their authorization (or with limited or altered authorization) to conduct the study, or to identify or recruit potential participants.

☐ No. I am not requesting to use source documents/materials that contain Protected Health Information (PHI) of persons (living or dead) without their authorization (or with limited or altered authorization) to conduct the study, or to identify or recruit potential participants.

27.2 * Are you proposing to collect Protected Health Information for research purposes?

☒ Yes

☐ No

28.0 (3460) Section A: Protected Health Information (PHI)

28.1 * Briefly describe the Protected Health Information (PHI) to be used in the research activity. If this study involves a review of records for which all the records will be in existence and completed at the time that the study is initiated, then specify the beginning and ending dates of those records.

The patient names and contact information that the health care providers will share with the PI is considered protected health information.

28.2 If Protected Health Information (PHI) will be disclosed to the investigator by another covered entity or entities, briefly describe these entities.

The patient names and contact information that the health care providers (general participants) will share with the PI is considered protected health information. The general participants who may share this information with the PI include end of life, Palliative, and Acute Care Administrators, Hospice and Palliative Care Nurses, Case Managers, Social Workers, Rural Minister/Spiritual Counselors, and physicians.

28.3 * Briefly explain who will receive and use the Protected Health Information (PHI) and where it will be stored.

The PI will receive this information and once contact is made with the patient, all names and contact information will be shredded and destroyed.

29.0 (3462) Section B: Use of PHI

29.1 * Protected Health Information (PHI) will be used:

- ☐ for the conduct of the study itself.
- ☐ to identify potential participants for recruitment.
- ☒ to contact potential participants regarding study participation.

30.0 (3464) HIPAA Alteration

30.1 * Please describe briefly the proposed alteration of the authorization. At the end of this application, you will be asked to attach a copy of the altered authorization section of the consent form. If this question does not apply, please type "n/a."

n/a

31.0 (3466) HIPAA Waiver or Alteration

31.1 * Briefly describe the plan to protect the Protected Health Information (PHI) identifiers.

The PI will receive this information and once contact is made with the patient, all names and contact information will be shredded and destroyed at the earliest opportunity.

31.2 * Briefly describe the plan to destroy the identifiers at the earliest opportunity consistent with the conduct of the research. If there is a justification for retaining the identifiers or such retention is otherwise required by law, this should be explained.

The PHI identifiers will be shredded and destroyed at the earliest opportunity and no PHI identifiers will be retained.
31.3 * Will the Personal Health Information (PHI) be reused or disclosed to any other person or entity?
☐ Yes ☒ No
31.4 * Is it true that the Personal Health Information (PHI) will not be reused or disclosed to any other person or entity EXCEPT as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of the PHI is approved by the IRB?
☒ True. PHI will not be reused or disclosed unless as excepted above. ☐ Not true. PHI may be reused or disclosed.
31.5 * Briefly explain why you must have access to the PHI in order to complete your research.
The patient names and contact information will be shared by the health care providers with the PI in order to recruit key participants for the research study.
32.0 (3467) HIPAA Alteration Practicality
32.1 * Briefly explain why the research activity could not practicably be conducted without alteration of the authorization requirement.
n/a There are no altered authorization sections of the consent forms. You may refer to section 20(participant recruitment) and section 26 (consent process)
33.0 (10000) Routing for Signatures and Attaching Documents
33.1 The following text box is provided in the event that you need to share additional information with the Review Board.
33.2 After clicking the "Save and Continue" button, you will advance to the routing form in order to attach any supporting documents (such as consent forms) and to send the submission to the necessary personnel for their signatures. Please Click on "Save and continue..."

Appendix I

Permission to use UTK IRB Approval to Collect Data at Cookeville Regional Medical Center



John R. Beal
Chief Legal Counsel
1 Medical Center Blvd
Cookeville, TN 38501
(931) 783-2008
Fax (931) 526-8814
jbeal@crmchealth.org

March 2, 2016

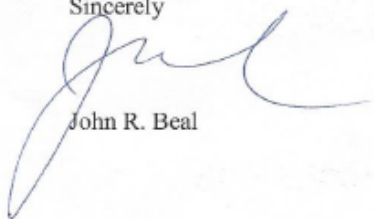
Mary Lou Fornehed, MSN, ACNP-BC
Tennessee Technological University

Dear Ms. Fornehed

Please accept this letter as acknowledgement that Cookeville Regional Medical Center will accept an IRB approval from The University of Tennessee Review Board for the research project that you will be conducting at our institution. We would need a copy of the protocol and a copy of the IRB approval letter. The approval letter should specifically state that Cookeville Regional Medical Center is an approved site for conduct of the research.

If you have any questions do not hesitate to contact my office. Please send all of the documents to my office.

Sincerely



John R. Beal

Appendix J1

Key informant Interview Guide

Interview Guide for Key Participants (Rural Appalachians)

ETHNODEMOGRAPHICS	
☐ Rural Appalachian with life-limiting illness ☐ Family member(s) ☐ Other _____	
How identify as rural Appalachian:	Location in rural Appalachia
Receiving palliative/EOLC: ☐ Y ☐ N	
Palliative/EOLC services used: ☐ Home Hospice ☐ Inpatient Hospice ☐ Inpatient Hospice (free standing) ☐ Inpatient palliative care (acute care setting) ☐ Inpatient palliative care (SNF) ☐ Palliative chemotherapy/radiation ☐ Home Health Care ☐ Physical therapy ☐ Occupational therapy ☐ Speech therapy ☐ None	
Age:	Sex: Place of birth:
Diagnosis:	Places lived:
# Of years with diagnosis:	
Years in current city:	Interview date(s):
Languages spoken:	Agency used if applicable:
Religion:	Insurance:
Employment/Occupation:	Code Status:
Education:	Advance Directives: ☐ Y ☐ N

Sample Open-ended Questions: These unstructured, open-ended questions guide systematic inquiry. Content and context of interviews will emerge as participants move at their own pace.

Care (Professional and Generic)

- I understand that you and your family have been dealing with a life-limiting illness. Please tell me about your experience. (Professional care)
- Please describe decisions that have been made during this time. (generic care)
- Please tell me about things that have helped you and your family make decisions.
- Tell me about things that made the decision-making process more difficult.
- Has your family assisted in or been the primary decision maker?
- Tell me about the care, if any, you have received from nurses or physicians or other members of the health care team with your decision-making at EOL.

Cultural Factors

Health Expressions, Patterns, and Practices

I am interested in learning about what is on your mind as you deal with decision-making at EOL?
 Feelings, views, joys, concerns, issues / philosophy / outlook / viewpoints

IRB NUMBER: UTK IRB-16-03389-XP
 IRB APPROVAL DATE: 01/23/2017

Tell me about your comfort when discussing life-limiting illness, death, and associated decision-making.

Religious/Spiritual Factors

Tell me about your spirituality/faith beliefs as you and your family deal with decision-making at EOL.

Kinship/Social Factors

Describe your support system.

Tell me about your family and any influence they had when decision-making at EOL.

What do you feel have been barriers/facilitators to the process of family decision making at this time during their lives?

Economic Factors

Please describe any influence economics may or may not have had on you or your as you are making decisions at EOL.

Environmental Factors

Tell me about the resources that are available near your home to assist you with decision-making at EOL and care at EOL.

Closing

Is there anything else you want to tell me about your family decision-making at EOL?

And any health care providers' actions that could have facilitated you and your family in your EOL decision-making?

Environmental Observations

Symbols

Nonverbal expressions

Brief Description of interview location and environment.

Appendix J2

General informant Interview Guide

Interview Guide for General Participants:
EOL, Palliative, and Acute Care Administrators, Hospice and Palliative Care Nurses, Case Managers, Social Workers, Rural Minister/Spiritual Counselors, Health Care Providers

ETHNODEMOGRAPHICS	
Palliative/Hospice Care Healthcare Provider or Community Member/Leader Role: ☐ RN ☐ HH Nurse ☐ MSW ☐ Case Manager ☐ Pastoral Care ☐ PT ☐ OT ☐ ST ☐ Physician/Provider ☐ Other _____	
Agency Affiliation	Length of time worked in current role:
Agency Location/Service Area	Time in current position:
Sex:	Years in professional role:
Age:	Education:
Place of birth: Places lived:	Highest degree obtained
Years in current city:	
Ethnic Heritage	
Languages spoken:	
Religion:	Interview date(s):

Sample Open-ended Questions: These unstructured, open-ended questions guide systematic inquiry. Content and context of interviews will emerge as participants move at their own pace.

Care (Professional and Generic)

Tell me about the care you provide rural Appalachian persons and families who are engaged in decision-making at EOL. (Professional care)

How would a healthcare provider determine appropriateness for this type of care? Engage in a conversation with a person or family member?

Please describe a caring nurse/healthcare provider/member of the interdisciplinary team when helping persons and families make decisions at EOL.

Describe Barriers or Facilitators to such care.

Tell me about any personal or professional experiences you have had with EOL decision-making, palliative, or EOLC?

Tell me about the family expressions and practices you have observed among rural Appalachians dealing with decision-making at EOL (generic care)

Describe what you have observed when family members care for one another during this process.

Describe what you have observed when family members are not caring/in conflict during this process.

Tell me about what you have observed in families related to use of folk care and seeking professional care.

Tell me about actions you have taken or wish you would have taken, or have observed other interdisciplinary team members taking to support families during decision-making at EOL.

IRB NUMBER: UTK IRB-16-03399-XP
IRB APPROVAL DATE: 01/23/2017

Cultural Factors

Health Expressions, Patterns, and Practices

I am interested in learning about what you believe is on the minds of rural Appalachian persons who are dealing with decision-making at EOL?

Feelings, views, joys, concerns, issues / philosophy / outlook / viewpoints

Tell me about the comfort level of families in discussing life-limiting illness, death, and associated decision-making.

Religious/Spiritual Factors

Tell me about the spirituality/faith beliefs you have observed in people and their families as they deal with decision-making at EOL.

Describe any fatalistic beliefs you may have observed.

Tell me about any influence your spirituality or faith may have (helped or hindered) in your work with families making decisions at EOL.

Kinship/Social Factors

Describe the support systems and family support you have observed among rural Appalachian persons and families who are dealing with decision-making at EOL.

Please describe the process for involving the person with a life-limiting illness and their family in making decisions for palliative/EOLC.

What do you feel have been barriers/facilitators to the process of family decision making at this time during their lives?

Have you or do you involve other members of the palliative/EOLC interdisciplinary team when discussing care and decisions with the person and family?

Economic Factors

Please describe any influence economics may or may not have had on family decision-making at EOL.

Environmental Factors

Tell me about the resources available in rural Appalachia that assist rural Appalachian persons who are dealing with decision-making at EOL and possibly seeking EOLC.

Closing

Is there anything else you want to tell me about rural Appalachian family decision-making at EOL? And any actions health care providers can take to facilitate meaningful care?

Environmental Observations

Symbols

Nonverbal expressions

Brief Description of interview location and environment

Appendix K

Leininger's Phases of Ethnonursing Data Enabler

Fourth Phase (Last Phase)

Major Themes, Research Findings, Theoretical Formulations, and Recommendations

This is the highest phase of data analysis, synthesis, and interpretation. It requires synthesis of thinking, configuration analysis, interpreting findings, and creative formulation from data of the previous phases. The researcher's task is to abstract and confirm major themes, research findings, recommendations, and sometimes make new theoretical formulations.

Third Phase

Pattern and Contextual Analysis

Data are scrutinized to discover saturation of ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meanings-in-context and along with further credibility and confirmation of findings.

Second Phase

Identification and Categorization of Descriptors and Components

Data are coded and classified as related to the domain or inquiry and sometimes the questions under study. *Emic* or *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

First Phase

Collecting, Describing, and Documenting Raw Data (Use of Field Journal and Computer)

The researcher collects, describes, records, and begins to analyze data related to the purposes, domain of inquiry, or questions under study. This phase includes: Recording interview data from *key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the DOI or phenomenon under study mainly from an *emic* focus. Attention to *etic* ideas is also recorded. Field data from the condensed and full field journal can be processed directly into the computer and coded, ready for analysis.

Source: McFarland, M. R. & Wehbe-Alamah, H. B. (2015). Leininger's enablers for use with the ethnonursing research method. In M. R. McFarland and H. B. Wehbe-Alamah (Eds.), *Leininger's culture care diversity and universality: A worldwide nursing theory* (3rd ed., p. 89). Burlington, MA: Jones and Bartlett Learning. Used with permission (in the process of obtaining) Jones and Bartlett Learning.

Appendix L

Leininger-Templin-Thompson-Ethnoscript Coding Enabler

Code Numbers, Categories, and Domains of Information: (Includes processing of observations, interviews, interpretations, material, and nonmaterial data)

Code Numbers Categories and Domains of Information

Category I: General Cultural and Holistic Domains of Inquiry

- | | |
|---|---|
| 1 | Worldview |
| 2 | Cultural–social lifeways and activities (typical day/night) |
| 3 | Ethnohistorical (includes chrono-data, acculturation, cultural contacts, etc.) |
| 4 | Environmental contexts (i.e., physical, ecological, cultural, social) |
| 5 | Linguistic terms and meanings |
| 6 | Cultural foods related to care, health, illness, and environment |
| 7 | Material and nonmaterial culture (includes symbols and meanings) |
| 8 | Ethnodemographics (numerical facts, dates, population size, and other numerical data) |
| 9 | * |

Category II: Domain of Cultural and Social Structural Data

(Includes normative values, patterns, functions, and conflicts)

- | | |
|----|---|
| 10 | Cultural values, benefits, norms |
| 11 | Economic factors |
| 12 | Educational factors |
| 13 | Kinship (family ties, social network, social relationships, etc.) |
| 14 | Political and legal factors |
| 15 | Religious, philosophical, and ethical values and beliefs |
| 16 | Technological factors |
| 17 | Interpersonal relationships (individual groups or institutions) |
| 18 | * |
| 19 | * |
-

Code Numbers	Categories and Domains of Information
Category III: Care, Cure, Health (Wellbeing), and Illness of Folk and Professional Lifeways and Systems	
20	Folk (includes popular health and illness benefits, values, and practices)
21	Professional health
22	Human care/caring and nursing (general beliefs, values, and practices)
23	Folk care/caring (emic or indigenous beliefs, values, and lifeways)
24	Professional care/caring (etic beliefs, values, lifeways)
25	Professional nursing care/caring (etic and emic) lifeways (congruence and conflict areas)
26	Noncare/caring beliefs, values, and practices
27	Human cure/curing beliefs, values, and practices
28	Folk and generic cure/curing (etic beliefs, values, and practices)
29	Professional cure/curing (etic and emic perspectives)
30	Alternative or emerging care/cure systems
31	*
32	*
33	*
34	*
Category IV: Health Care, Social Structure Institutions/Systems	
(Includes administrative norms, beliefs, and practices with meanings-in-context)	
35	Cultural-social norms, beliefs, values, and context
36	Political-legal factors
37	Economic factors
38	Technological factors
39	Environmental factors
40	Educational factors (formal and informal)
41	Social organization or structural factors
42	Decisions and action patterns
43	Inter and multidisciplinary norms, values, and collaborative practices
44	Nursing specialties and features
45	Non-nursing specialties and features
46	Ethical/moral care-cure factors
47	*
48	*
49	*
Category V: Life Cycle with Inter- and Intragenerational Patterns	
(Includes ceremonies, beliefs, and rituals)	
50	Life cycle male and female enculturation and socialization processes
51	Infancy and early childhood years
52	Adolescence (or transitions) to adulthood
53	Middlescence years
54	Advanced years
55	Cultural life-cycle values, beliefs and practices
56	Cultural life-cycle intra and intergenerational conflict areas
57	Special life-cycle subcultures and groups
58	Life passages (includes birth, marriage, death)
59	*
60	*

Code Numbers	Categories and Domains of Information
Category VI: Methodological, Reflections, Issues, and Research Features	
61	Specific methods or techniques used
62	Key informants
63	General informants
64	Enabling tools or instruments used
65	Problem areas, concerns or conflicts
66	Strengths, favorable and unanticipated outcomes of researcher or informants, subjective data and questions
67	Unusual incidents, interpretations, questions, etc.
68	Factors facilitating or hindering the study (time, staff, money, etc.)
69	Emic data methodological issues
70	Etic data methodological issues
71	Dialogue by interviewer
72	Dialogue by someone other than informant or interviewer
73	Additional contextual data (includes nonverbal symbols, total view, environmental features, etc.)
74	Informed consent factors
75–100	*

*Denotes areas where researcher adds own additional codes and descriptions

Source: Adapted as an enabler by Wehbe-Alamah, H. B. & McFarland, M. R. from the original document by Leininger, M.; Templin, T.; Thompson, F. (1991). *The Leininger-Templin-Thompson Ethnoscrypt Qualitative Software Program User's Handbook* (pp. 16-19), Wayne State University (MI), the Madeline M. Leininger Collection on Human Caring and Transcultural Nursing (ARC-008, Folder 6-29). Retrieved from the Archives of Caring in Nursing, Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, FL. Used with permission from Florida Atlantic University and The Archives of Caring.

Vita

Mary Lou Clark Fornehed was born and raised on a farm in a rural area of the Cumberland Plateau in rural Appalachia. She was the granddaughter of physician Dr. Erbie Clark, Sr. who envisioned and began the process of establishing the first acute care facility in his small rural town. The stories of her grandfather's unending love and kindness for their community and the persons he served intrigued and encouraged her to consider a profession where she could care for others. Mary Lou's bachelor of science in nursing degree was obtained from Tennessee Technological University in 1986. Soon realizing she wanted to know more about critical care nursing, she went back to school and graduated with her master of science in nursing from Vanderbilt University in 1990. Mary Lou completed her credentialing exam for the Acute Care Nurse Practitioner certification in 1997, and has worked in critical care nursing as either a registered nurse or an acute care nurse practitioner since 1997.

Mary Lou's love of teaching and being a nurse in her rural Appalachian community was the catalyst for her journey in doctoral work. She started in the PhD program at the University of Tennessee, Knoxville in 2012, receiving a post-masters certificate in nursing education in 2016. This doctoral dissertation fulfills the completion of a doctoral degree in nursing from the University of Tennessee, Knoxville in 2017.