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Culturally Congruent End-of-Life Care for Rural Appalachian People and Their Families

Sandra J. Mixer, PhD, RN, CTN-A [Assistant Professor],

University of Tennessee, Knoxville

Mary Lou Fornehed, MSN, RN, ACNP-BC [PhD Student],

University of Tennessee, Knoxville

Jason Varney, MSN, RN, FNP-BC [Formerly Graduate Student], and

University of Tennessee, Knoxville, Nurse Practitioner at Knoxville Orthopaedic Clinic

Lisa C. Lindley, PhD, RN [Assistant Professor]

University of Tennessee, Knoxville

While the process of dying is a universal human experience, it amplifies peoples' cultural similarities and differences.¹ Professional nurses have a duty to provide culturally congruent care (CCC) that is satisfying, meaningful, and beneficial, fits with peoples' daily lives and, in this context, helps them face end of life (EOL).² Knowing the values, beliefs, and practices of patients and families experiencing EOL challenges is essential to delivering quality health care, addressing health disparities, and achieving a "dignified death."^{3–5} Yet, little is known about culturally congruent end-of-life care (CC-EOLC) needs of rural Appalachians.

Appalachian people have a unique geographic, cultural, and economic heritage.^{6,7} They represent a large group of Americans who have been traditionally under-represented in healthcare studies in general, and in cultural care research specifically. As a group, they have been misunderstood, ridiculed, stereotyped, and called "stupid," "rednecks," and "hillbillies." Appalachians' rich cultural values and beliefs include a sense of belonging, love of "our mountains," strong family ties, firm faith, appreciation of hard work, fierce independence, self-reliance, and pride.^{6–8} The Appalachian area also is impoverished. For example, all 36 counties in the Appalachian region of East Tennessee are designated by HRSA as *medically underserved*, and 22 of these are *health professional shortage areas*.⁹ In these counties, the percentage of the population living below the poverty level is 19%, compared to 15.8% in Tennessee overall, and 13.0% in the United States.¹⁰ Limited access to healthcare services, specifically EOL care, in this rural setting creates vulnerabilities in this population.¹¹

Background and Significance

Providing CC-EOLC for rural Appalachians is complex. Many factors make this culture rich and diverse including the values of rugged independence and a distrust for outsiders; the geographical challenges of mountains and harsh winter weather; the ideals of faith, family, and community; and the confounding variables of educational disadvantage, low socioeconomic status, and poverty.^{6,12} Appalachian people reside in a vast portion of the United States. While, there is no consensus about the geographic borders of Appalachia, in 2005 the federal government defined the area as encompassing 410 counties in portions of 13 states, extending from New York to Mississippi. Editors of the *Encyclopedia of Appalachia* have defined the “core” region as including northern Georgia, eastern Kentucky, western North Carolina, east Tennessee, southwestern Virginia, and West Virginia.¹³ This study focused on the rural Appalachian region of east Tennessee. Historically, in search of work, education, and a better life, Appalachian people migrated to cities such as Cincinnati, Detroit, and Chicago.¹³ Appalachian cultural roots run deep and these cultural values, beliefs, and lifeways are dynamic and persistent. At the time of dying, familial cultural roots surface and are accentuated.^{1,13}

The importance of providing CC-EOLC, the need for staff education, and the demand for additional research to understand culture specific factors surrounding end-of-life care (EOLC) is clearly articulated in the literature.^{1,3,14–15} Studies demonstrate that combining generic (folk) and professional (nursing) care is essential to providing CCC.⁸ While a synthesis of 15 qualitative studies revealed conceptualizations of hospice among culturally diverse populations, no Appalachian cultural perspective was represented.¹ One narrative analysis discussed the complexity of death and the desire to return to rural Appalachian cultural roots to die.¹⁶ Another study used story theory to understand rural Appalachian patients’ cultural/religious beliefs and practices to enable culturally appropriate health promotion intervention.¹⁷

Qualitative study established the importance of understanding from the patient’s perspective the meaning and quality of EOLC in developing nursing care.¹⁸ The use of home remedies and spiritual care in home settings among Black caregivers in Nova Scotia,¹⁹ the influence of Dutch-reformed Canadian culture on family caregiving in the home,²⁰ and the role of faith for African Americans living at home with life-limiting illness²¹ have been described. Several ethnographic studies have explored rural Appalachian cultural factors, including faith and family values influencing health;⁶ the characteristics of spirituality in women;²² and older women living independently.¹² These findings suggested the importance of honoring cultural values and beliefs in providing culturally congruent nursing care. No studies were found that addressed rural Appalachian persons receiving EOLC or their culture care needs.

There is insufficient evidence about the generic (folk) and professional (nursing) interventions that promote CC-EOLC for rural Appalachians. When nursing care and interventions are not culturally acceptable, people may not follow recommendations and may experience dissatisfaction with care.^{3,5} Research to understand the culture care needs of rural Appalachians at EOL is essential to address this gap in knowledge and develop

strategies to promote a satisfying death experience for this underserved cultural group. Therefore, the purpose of this study was to describe generic (folk) and professional (nursing) factors that healthcare providers can apply to promote CCC for rural Appalachian people at EOL. The research questions were: 1. What are the uses and meanings of folk care among Appalachian patients and their families at EOL within their home and community contexts? 2. What is the comparison of the use and meaning of professional nursing care with Appalachian people at EOL? 3. What are the patterns of support among family caregivers and patients at EOL?

Theoretical Framework and Method

The Culture Care Theory (CCT) and ethnonursing research method provided a holistic and comprehensive means to understand CC-EOLC for rural Appalachian persons and their families.⁵ Ethnonursing is a naturalistic, open discovery method that is derived from ethnography and used to systematically understand and interpret people's meanings, experiences, and lifeways: what they do and how they are in the world.⁵ The method embraces the importance of discovery from the people's (emic) way of knowing and gives credence to the professional nurse's (etic) way of knowing.²³

Leininger developed enablers to encourage participants to tell their stories and explicate culturally embedded, covert, and complex data. The *Sunrise Enabler*, a cognitive map of the theory,⁵ was used to depict the worldview, social structure dimensions, care expressions, patterns, and practices meaningful to Appalachian people at the end of their lives (Figure 1.). *Worldview* refers to the lens people use to see their world. Cultural and social dimensions include the range of generic (folk) and professional (nursing) factors to be considered when giving care. These dimensions can include technological, religious/philosophical, kinship/social, political/legal, economic, and educational factors, as well as cultural values, beliefs, and lifeways.⁵ Data from these factors guide the researcher in applying research findings to nursing care. The CCT predicts that, by using three modes of culture care decisions and actions—preservation/maintenance, accommodation/negotiation, and repatterning/restructuring—nurses can provide culturally congruent care. These modes/nursing interventions are derived from the synthesis and analysis of qualitative data.^{5,23}

The *Stranger to Trusted Friend Enabler* helped the researchers create trusting relationships with participants to obtain authentic, credible, and dependable data.²³ Additionally, hospice nurses, administrators, and community pastors served as gatekeepers to connect researchers with patient and family participants.

The following research assumptions derived from the CCT guided this study: 1. "Care is the essence of nursing and a distinct, dominant, central, and unifying focus"^{5(p. 18)}. 2. Care is essential for terminally ill people's wellbeing, health, healing, growth, and ability to face death. 3. Culturally congruent nursing care occurs when terminally ill people's culture care values, expressions, and patterns are known and used in meaningful ways by nurses.⁵

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.”²³ (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 researchers’ understanding of people’s meanings and experiences related to CC-EOLC.²³

Institutional review board approval was received and research participants were recruited through hospice providers and pastors from the region. Fifteen participants volunteered, provided consent, and engaged in open-ended interviews. Providers of hospice care recognize the person and family as the care unit. Therefore, key informants were six persons with life-limiting conditions and/or their caregivers. Eleven people were represented in the six key informant interviews. For example, one key informant receiving hospice care was interviewed in his living room while lying in a hospital bed. His wife and daughter, who were seated near the bed, also participated. Another key informant was a daughter who, at different times, had cared for her now deceased mother and father while they received hospice care. The six key informants consisted of three Caucasian men and three Caucasian women, ranging in age from 62–90, self-identified as Christians, who were born and raised in the east TN region. Their education ranged from second grade to graduate degree levels, each had a hospice length of stay greater than 180 days, and all were interviewed in their homes.

The nine general informants included four hospice/palliative care nurses, two hospice directors, one social worker, one pastor, and one physician. Among this group were four Caucasian men and five Caucasian women, aged 42–56, who self-identified as Christians. Seven were from the region and seven had graduate-level education.

Data Collection and Analysis

Data were collected over six months in face-to-face meetings and one phone call. Participants engaged in open-ended interviews using a semi-structured guide, which incorporated CCT constructs and reflected the research questions.²³ Participants were asked to tell the interviewer about the care they were receiving and the resources that assisted with their healthcare needs. Interviews were audio recorded, transcribed, and de-identified through coding. Field notes described the environmental context of interview settings, artifacts, nonverbal communication, and researcher thoughts, feelings, and reactions.²³

Graduate students participated in several interviews with the Principal Investigator. After their expertise was established, students conducted several interviews independently. All researchers listened to every interview and met as a team to conduct data analysis. Data were analyzed using the four phases of ethnonursing analysis for qualitative data.²³ In the first phase, raw data were collected and described. Culture care theoretical constructs, as depicted in the Leininger-Templin-Thompson Ethnoscience Coding Enabler, provided the coding structure for analysis.²⁴ ATLAS.ti™ qualitative software was used for data

management. Coding decisions were made as a group and memos documented thought processes and decisions.

In the second phase of analysis, data were studied for similarities and differences; patterns and ideas were identified in the third phase; and the fourth phase involved synthesis and abstracting themes. Finally, themes were used to identify nursing decisions, actions, and interventions for providing CC-EOLC. This study met the five qualitative criteria for ethnographic studies: credibility, confirmability, meaning-in-context, recurrent patterning, and saturation.²³ Interviews were conducted until data saturation occurred. Data were continuously transcribed throughout the study, preliminary analyses were made, and researchers remained open to new insights. When repetition of data occurred and no new findings were discovered, saturation was met and data collection ended. Findings were traced back to the raw data, creating an audit trail. Being immersed in the research setting over a six month period allowed researchers to note recurrent patterning which confirmed that repeated themes and patterns were consistently displayed over time.²³ Digital interview files were kept on password protected computers and paper files kept in a locked file cabinet in the lead researcher's office. They will be stored for three years and then destroyed (paper shredded and digital files erased).

Findings

Four major themes were extrapolated from the data. Within the CCT, data is on a continuum and can tend toward universalities/similarities or diversity/differences. Themes with universal and diverse patterns are supported by salient participant quotes and reported in Table 1.

Theme One - Faith

The first theme formulated was *Faith is fundamental to rural Appalachians and their transition through EOL*. This theme was derived from patients, families, and general informants' reflections and descriptions of their faith as fundamental to them and how they conduct their daily lives. Three care patterns supported this theme: rural Appalachians refer to their supreme being as "God," "Lord," or "Jesus;" their faith practices of Bible reading and prayer; and their view of God's timing for healing and death. Specific key and general informant quotes provided the raw data supporting the theme and patterns. One pastor shared the great religious diversity in rural Appalachia. He described Roman Catholic, Eastern Orthodox, Southern Baptist, Black Baptist, Black Methodist, White Methodist, and Lutheran congregants.

Theme Two – Family Care

The second theme was *Family care at EOL is essential for culturally congruent care*. Two universal patterns were formulated from participants who spoke extensively about their desire to care and be cared for by loved ones at home and to spend quality family time at EOL. The third pattern was diverse and addressed how some family members bear the bulk of care giving while others did not participate. Many participants described cohesive family units while others related stories of family conflict that interfered with care giving

responsibilities. Some children provided care for their parents despite their own illnesses and financial burdens.

Theme Three – Generic and Professional Care

Integrating generic and professional care is essential for culturally congruent EOL care emerged as the third theme. The first universal pattern identified participants' desire for integrating generic/folk care into their EOLC. The second universal pattern related to patients and families expecting interdisciplinary hospice team members to demonstrate trusting and caring behaviors. Families valued and expected hospice providers to blend folk remedies with generic and professional care. The third pattern demonstrated diversity in that many church communities provided caring support while some church members did not know how to help. A non-caring fourth pattern emerged: no pediatric hospice care services were provided within this rural Appalachian area.

Theme 4 – Decision Making

Theme four was *Rural Appalachian families vary in their decision-making about hospice care*. Two universal care patterns emerged from this theme. Rural Appalachian families made the decision to start hospice care based on their need for help, caregiver exhaustion, and/or pain and symptom management. The second pattern was rural Appalachian families chose not to receive hospice care based on the desire to continue curative care or avoid the stigma of death. Participants suggested educating rural Appalachian people about the role of hospice in caring for loved ones at EOL. They stressed this message would be best delivered by trusted fellow rural Appalachians and the church using videos that could be shared with extended family members at home. Two caregivers proposed teaching congregants how to serve others at EOL.

Discussion

In one of the first studies to examine CC-EOLC for rural Appalachians, researchers used the ethn nursing method, guided by the CCT to discover generic/folk and professional nursing care that is satisfying, meaningful, fits with peoples' daily lives and helps them face EOL.

Nursing Practice Implications

Using the CCT, researchers synthesized data from the themes, patterns, and quotes to make recommendations for providing CC- EOLC (Table 2). Culture care preservation/maintenance, accommodation/negotiation, and repatterning/restructuring refer to nursing decisions and actions that help rural Appalachians achieve their desired EOLC.²³

Contribution to Nursing Theory

Three of Leininger's 11 theoretical assumptions were adapted for and subsequently supported in this study. Three existing CCT care constructs were found to be important for these rural Appalachian participants: respect, spiritual care, and family care.^{5,8} Within the CCT, care constructs are embedded in peoples' values, beliefs, and practices and their discovery helps nurses understand the meaning of care at EOL. Continued study of these constructs can further clarify knowledge about the roots of human caring and health and

build knowledge for the nursing discipline. Participants reported that the care construct of respect was best demonstrated by integrating generic/folk with professional care and treating people “as if they were their own.” Studies have demonstrated that respect is the most valued and frequently identified care construct across cultural groups in a variety of contexts.^{8,25}

Since faith in God was essential to participants’ EOL transition, spiritual care provided by church members and interdisciplinary team members was highly valued. Consistent with previous studies, participants described a personal relationship with God and their faith as central to decision making, coping, and making meaning of their lives.^{21,26,27} Participants suggested that church communities be used to teach rural Appalachians about hospice care and supporting people at EOL. Studies have demonstrated the effectiveness of churches in promoting positive health behaviors among rural Appalachians.^{28,29} Further research is needed about the role of churches in meeting rural Appalachian congregants’ EOLC needs.

Family care was expressed by participants’ desires to care for and honor dying loved ones by helping them remain at home. Families were found to be essential in two other ethn nursing EOL studies, with some diversity. Yupik Eskimo considered community members as family and they preferred to receive EOL care in their home or rural/bush community.³⁰ Gates described Anglo- and African-American families and patients supporting each other in two urban institutional settings: a freestanding hospice and a large teaching hospital’s oncology unit.³¹

This study’s findings revealed a lack of pediatric hospice services in the area. This is consistent with recent study findings exploring geographic access to pediatric hospice care. Those authors found that, although there was a consistent need for services in rural Appalachia, hospice providers did not meet the needs for pediatric EOLC.³²

Therefore, researchers should continue exploring issues surrounding the provision of pediatric hospice care.

Limitations

These findings should be considered in light of several limitations. All participants self-reported Christian faith. Since not all rural Appalachians are Christians, and Christians have varying values and beliefs, nurses are encouraged to assess people’s spiritual care needs. Study participants were from the East Tennessee region. Some of their culture care needs may be unique and could limit transferability of these findings to other regions. In addition, people of rural Appalachian heritage have migrated throughout the country. Therefore, nurses again are encouraged to assess individual patients’ and family members’ cultural needs to consider the application of these findings. While fifteen participants provided important data for understanding CC-EOLC for rural Appalachians, additional research is needed to discern if these culture care needs are shared across the broader rural Appalachian region.

Conclusion

This study addressed a gap in the literature by discovering the culture care EOL needs of rural Appalachian persons and their families at home. Themes abstracted related to faith, family care, integrating generic/folk and professional nursing care, hospice care decision-making, and recommended nursing interventions promote a satisfying death experience for this population. These findings are useful for nurses in practice, specifically those caring for underserved populations and rural residents. Educators and preceptors may use findings to teach nursing students and nurses how to provide culturally congruent care for dying persons.

This research also confirmed the usefulness of the culture care theory and ethnonursing method in this context, thus contributing to the body of transcultural nursing and EOLC knowledge. These findings lay the foundation for future work focused on developing culturally congruent EOLC nursing interventions. Since death is a part of life that eventually affects everyone, applying knowledge about personal and family values, beliefs, and practices at EOL is essential for promoting physical, emotional, and spiritual health, addressing health disparities, and facilitating a dignified death among rural Appalachians.^{6,14-18}

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Figure 1.
Leininger's Sunrise Enabler for Discovering Culture Care

Table 1

Patterns and Quotes for Four Themes Extrapolated from the Data

Recurrent Care Patterns	Salient Participant Quotes <i>Key Informants are quoted unless indicated as GI (General Informant)</i>
Theme One - Faith is fundamental to rural Appalachians and their transition through EOL.	
Faith in "God, Lord, Jesus"	<p>"Almost every Sunday, you hear some expression, the reference, the verse in the bible pertaining to love and then you begin to think what the good Lord did with His Son Jesus and what kind of love that took. And then for the first time, then you begin to realize that life itself is important in terms of ... eternity because life here is so brief."</p> <p>"We believe in Jesus and that He died on the cross for our sins and when we die, we're going to heaven."</p> <p>"God has watched over me so many years and He healed me so many times now. You know we can do this with God's help."</p> <p>"You know this is mostly the Bible belt ... we do everything we can to honor and respect their beliefs, whatever [they may be]." (GI)</p>
Faith practices: Bible reading and prayer	<p>"I've wore that Bible out."</p> <p>"We got a lot of people praying for us."</p>
God's timing for healing and death	<p>"We, none of us know, so I believe in the Lord and I believe He'll take me when he gets ready ... for me to go."</p> <p>"They have stated that given the normal progression of disease, you will probably live about six, you know no more than 6 months, but God has his own timing."</p>
Theme Two - Family care at EOL is essential for culturally congruent care.	
Rural Appalachian participants wanted to receive EOL care at home.	<p>"...Honor thy father and mother."</p> <p>"You know, around here in the mountains, you know you take care of your people."</p> <p>"I had a rough time for about a year and a half there. 24 hours a day but we didn't put him in a nursing home."</p>
Rural Appalachian participants desired quality time with family during EOL care.	<p>"...as long as I have enough time with my son, I'll be fine."</p> <p>"I got so lonesome, you know, for my family and so I come back in order to spend the rest of my life with them."</p> <p>"A loving [grand]child will cure it all."</p>
Diverse pattern: Some family members provided care and some had conflict.	<p>Some children did not assist with caring for their parents and engaged in extensive conflict with the caregiver sibling when money was needed to assist with EOLC "Get a lawyer to fight the will ... why don't they wait till they die to fight over it? ... You all [referring to siblings] come down here and you can have everything. I will head back home. Good luck. They won't come."</p> <p>"Families that have five children, six children, 12 children and there's always usually one or two decision makers [about healthcare/finances] in that entire family system. And so you have 9, 10 people depending on one or two who have been the primary decision makers for that entire family." (GI)</p> <p>"...a lot of times families have a hard time...because they work and they maybe can't be there all the time." (GI)</p>
Theme Three - Integrating generic and professional care is essential for culturally congruent EOL care.	
Rural Appalachians integrate generic/folk care at EOL.	<p>"The friendship, somebody who just cares and trying to help me ... the medicine may or may not work ... all medicines don't work, but friendship is about the most wonderful aspect of care, for any person, I think."</p> <p>"Those machine feeders and artificial respirators and so forth that keep her going beyond her natural tendencies and we didn't like any of that."</p> <p>"[some] make Vaseline™ balls and coat with sugar and they eat it [for constipation]" (GI)</p> <p>"Poultice ...[to] draw the pain out"; "Certain kinds of tea and toddies"; "let the dog lick a sore to get better"; "rub honey on a sore leg"; occasionally marijuana for the appetite"; "warm water"; "herbs and greens [learned from grandmother]"</p>
Professional care must be based on trust and caring behaviors exhibited by hospice interdisciplinary team members.	<p>"Trust factor ... trust is one of the main things."</p> <p>"Home boy ... A local that knows ... your family and ... it's just good to be dealt with like that with somebody you know."</p> <p>"They treated them, I feel, as if they were their own, very loving, caring."</p> <p>"I mean the home health, ya' know, never show that it's just a job."</p> <p>"The bath lady, for instance, was very concerned about my dad and my mom. They treated them, I feel, as if they were their own. Very loving, caring and always pointed out 'Well, look at this' or 'look at that,' and 'what do you think' ... They would pass the word on ... to the nurse...to the doctor. I mean whatever needed to be taken care of, they did, and that was such a blessing."</p> <p>"I stayed in the kitchen with the wife and kind of gave her some extra support while the funeral home was taking him out because I can tell that was the part she really didn't want to see." (GI)</p>
Many church communities provide caring support for families at EOL and some	<p>"The people of the church were very helpful; as a matter of fact ... they still bring my dinner on Wednesdays."</p> <p>"A Christian church and they at different times brought meals every day."</p> <p>"I don't see how people make it that don't have a church family."</p>

Recurrent Care Patterns	Salient Participant Quotes <i>Key Informants are quoted unless indicated as GI (General Informant)</i>
church members don't know how to assist.	<p>"[The] church ... had prayer services for her"</p> <p>"And churches, people want to help. They want to help. It's just they don't know what to do and then you've got people like me that say 'No, we can do that. We'll do that. You don't need to come and help' ... you don't want to put anybody out ..."</p> <p>"All the diversity that's represented in these churches. It's hidden, in the hollers... So there's a lot more diversity in Appalachia, but with that, there's alienation." (GI)</p>
Non-care diverse pattern: There are no pediatric hospice care services in this geographic area of rural Appalachia.	<p>"[In the last] year [the] company has put in a policy that we are not to take pediatric patients anymore." (GI)</p> <p>"You know what happens with those kids and families and there's no [professional] support at home, which is horrible ..."(GI)</p>
Theme Four - Rural Appalachian families vary in their decision-making about hospice care.	
Rural Appalachian families made the decision for hospice care based on their need for help, caregiver exhaustion, and/or pain and symptom management.	<p>"When I decided that it was time that I needed more help, you know, in making all these decisions ... we started the hospice."</p> <p>"I think it was more so me, just to the end of my rope, that really made me decide."</p> <p>"... Because I needed more help ... [to] make all those decisions and because you get tired. You get worn out and you just physically feel numb part of the time. It's the hardest job I ever had in my life."</p> <p>"I got so much pain; I knew I needed to do something."</p> <p>"I still didn't say 'hospice' around mom and dad...I didn't want to say the word around em because I just didn't want em to think they were near death."</p> <p>"I think a lot of families also have the belief that hospice will perhaps be there all the time or provide more care then just, you know, an hour or two whenever they're needed. And they can easily get overwhelmed with taking care of the terminally ill person at home ..."(GI)</p>
Rural Appalachian families choose not to receive hospice care based on the desire to continue curative care or to avoid the stigma of death.	<p>"I mean truly you know the minister is praying for healing ... not for comfort... it is to heal the patient... [They] are usually the one who will stand down to the bitter end." (GI)</p> <p>[GI sharing what a family member stated] "'Daddy hasn't been baptized and he's going to hell. He can't die' and they believe that with all their heart ... So that can be another sticking point of letting somebody go because they feel that they will not be in a better place."</p> <p>"You can't do it all on your own and I think that most people around here, when you say hospice, that means death ... but it's not really, it's a blessing."</p> <p>"They just give you Morphine 'till you die."</p> <p>[GI in discussing the stigma of hospice with a family member] "She never was on hospice"... 'I wish you'd just change your name.' I'm like. 'I can't change the name.' They have to know they're on hospice." (GI)</p> <p>"It has to be their decision to elect hospice, but we really try to educate 'em 'cause there's such a stigma with hospice." (GI)</p>

Table 2

Nursing Decisions and Actions That Promote CC-EOLC for Rural Appalachians

Culture Care Preservation/Maintenance
<ul style="list-style-type: none"> • Preserve generic/folk and professional care practices: • Honor faith values, beliefs, and practices • Preserve strong family relationships by supporting the provision of care by family in the home • Maintain trusting and caring nursing practices (treat patients like family and be present)
Culture Care Accommodation/Negotiation
<ul style="list-style-type: none"> • Negotiate with church community to support families in homes at EOL (food, prayer, visits, and phone calls) • Accommodate desire to remain at home during EOL by negotiating use of interdisciplinary team services (home health aides for bathing, social worker for resources, pastoral care to mobilize church community, hospice volunteers) • Negotiate with families to use interdisciplinary team members for family conflict resolution as necessary
Culture Care Repatterning/Restructuring
<ul style="list-style-type: none"> • Propose legislative policy and corporate guideline changes to ensure pediatric palliative/hospice care services are provided throughout rural Appalachia