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Community-Academic Partnership

Intervention to Prepare Community Members for the End-of-Life Journey

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Despite research findings that rural Appalachians prefer to die at home, few people access palliative and hospice care services, and many report limited knowledge about palliative/end-of-life care resources. A community-academic partnership was formed to address this need. Train-the-trainer workshop and materials were co-developed. This study tested the feasibility and cultural acceptability of the training intervention to increase community members' knowledge about palliative/end-of-life care resources for East Tennessee Appalachian people. Community-based participatory research design and culture care theory guided the project, intervention, and research. After engaging in end-of-life training, participants completed a retrospective pretest-posttest survey. Paired samples *t* tests were used to compare knowledge before and after training. Means and standard deviations were used to report training material usefulness and cultural acceptability. Short-answer qualitative data were analyzed using content analysis. Sixty-six adults completed the survey. Ratings for training materials and cultural/theological acceptability were high. Participant knowledge rankings showed significant improvement after training at the $P < .001$ level. Qualitative feedback was positive. The training intervention was feasible, culturally acceptable, and effective for increasing East Tennessee Appalachian persons' palliative/end-of-life care knowledge. Community member expertise/collaboration integrated into every stage of the project is the bedrock of cultural acceptability and feasibility.

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Despite research findings that rural Appalachians in East Tennessee prefer to die at home, few people access palliative and hospice care services, and many report limited knowledge about palliative and end-of-life care (PEOLC) resources.[1-3] The American Nurses Association and the Hospice and Palliative Nurses Association have called for nurses to lead the transformation of PEOLC by addressing advocacy, access, education, and training needs.[4] Worldwide, it is estimated that more than 40 million persons with life-limiting illness are eligible for PEOLC; however, less than 14% will receive such care.[5] Considering the importance of ensuring access to PEOLC for all,[4] it is unfortunate that care is often limited in community-based and rural settings.[6] Most hospices operate in populated regions with only 18% serving rural areas.[7 ,p.316] Such limited access further contributes to health care disparities for many rural underserved persons.[6,7]

The East Tennessee region of rural Appalachia has some of the most impoverished counties in the state of Tennessee.[8] Residents reflect rural Appalachian cultural values and beliefs of strong family and community ties, firm faith, hard work ethic, fierce pride, and independence.[9] Unfortunately, there is also limited access to health care, with many counties designated as medically underserved[10] and health provider shortage areas.[11] In the county where the community-academic partnership was formed, approximately one-fifth (22%) of residents live in poverty[8] compared with 14% in Tennessee[8] and 12% in the United States.[12] Low health literacy, limited education, and rural and mountainous geographic terrain further limit residents' access to PEOLC services.[1,2,9] This article presents a community-academic partnership formed to address these PEOLC needs, intervention and evaluation tool development, and feasibility and cultural acceptability results.

REVIEW OF LITERATURE

Previous research identified that many East Tennessee rural Appalachian families, neighbors, and community members lack knowledge about PEOLC options and how to help

others facing PEOLC challenges.[1,2] Patients and families interviewed suggested that the most culturally congruent way to teach rural Appalachian families about PEOLC is through trusted local individuals from their own churches and community organizations.[1,2] Research participants recommended using digital formats such as videos to enhance health literacy and educate extended family members at home.[1]

Studies have demonstrated the effectiveness of using train-the-trainer (TTT) models[13,14] and culturally acceptable faith-based interventions in communities to disseminate health information, promote chronic disease management, improve community health, and ensure intervention sustainability.[13,15-17] Researchers reported that health education should be co-developed with community partners to reflect people's values and ensure cultural and theological acceptability.[16-18] However, community/faith-based partner involvement varied considerably. Although several studies reported only using partners to adapt a premade educational program,[13,16] 1 study tailored an intervention to each of 74 participating African American churches,[17] and another engaged Appalachian community and faith leaders in every aspect of intervention—from development through implementation.[18]

In their systematic literature review, researchers found that advance care planning education was effective when delivered within a trusted faith-based local community.[19] Furthermore, they identified the importance of programs that reflect the cultural values and beliefs and "preserve a spiritual/Biblical context."[19(p5)] In summary, using co-developed, faith-based interventions is a promising way to reach underserved populations and address health disparities. In addition, the strategy of using TTT format to train trusted community members facilitates delivery of culturally sensitive interventions. Therefore, the purpose of this study was to test the feasibility and cultural acceptability of a PEOLC training intervention to increase community members' knowledge about PEOLC for East Tennessee Appalachian people.

Community-Academic Partnership and Intervention

A community-academic partnership was formed to increase families' and community members' knowledge about and use of PEOLC services in a rural area of East Tennessee. The partnership included an interdisciplinary team of church and community members (15), pastors (2), interprofessional health care providers (5), academics (9), and county extension agents (3) that collaborated to use best practices, research, cultural knowledge, and expertise to co-design the training intervention.

Community partners were essential in designing the intervention and educational materials to meet the needs of people in the community. For example, these partners emphasized addressing PEOLC from birth to old age; practical tips about how to help others, including children; culturally acceptable wording such as "help" versus "advocate"; determining video content and participant testimonials; and evaluation tool format and wording. Partners named the training "Honoring Life's Journey" and designed a logo that represented community values (available upon request).

Training materials addressed (*a*) "why talk about PEOLC?", (*b*) how PEOLC services support patients and families, (*c*) how to access care, (*d*) how hospice is not giving up, and (*e*) how to help others including children facing PEOLC. Later, on the basis of community member and trainer feedback, advance care planning was added. A PowerPoint presentation included these points, and community member videos described local, personal experiences. "Take-home resources" were (*a*) a brochure summarizing covered points and (*b*) a DVD video. To accommodate health literacy challenges, materials were designed at the fifth-/sixth-grade reading level, and videos assisted persons with no/limited reading skills.

Community members used these resources to teach people about PEOLC in a TTT format. Training sessions were held at community sites and homes (see Study Procedures). Each session lasted 1 to 1.5 hours and began with "share cards," which were used to facilitate participant interaction in small groups. Examples of discussion questions were as follows: What does quality of life mean to you? What scares you most about the dying process? Why do you think it is important to talk about death? Trainers used the PowerPoint slides with notes for their presentations and encouraged participants to ask questions throughout. Hospitality is a cornerstone of Appalachian culture; therefore, refreshments were usually served.

The partnership goal was to provide proactive PEOLC education so that knowledge gained could contribute to quality of life and a dignified death experience for people, their families, and community members. The 4-year project plan is depicted in Figure 1.

Theoretical Framework and Research Design

The study was guided by the culture care theory.[20] The goal of the theory is to provide culturally congruent care that contributes to people's holistic health, well-being, disability, illness, or dying. Culturally congruent care is care that is "satisfying, meaningful, and beneficial; fits with people's daily lives; and, in this context, helps them face end of life."[1(p526)] Community-based participatory research (CBPR) design engaged community members in all aspects of the project.[21] Community-academic partners collaborated to define the research questions, co-designed the PEOLC training intervention and evaluation forms, served as trainers, collected data, and interpreted and disseminated results. Community member involvement at every step of the research process contributes to culturally acceptable methods and outcomes.[20,21] The culture care

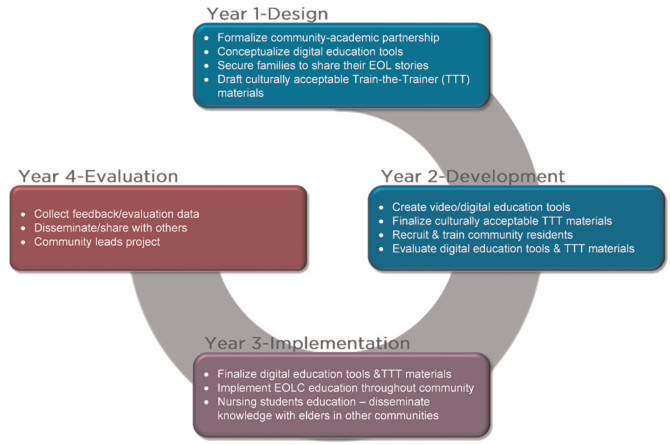

FIGURE 1. Community-academic palliative/end-of-life education project plan. EOLC, end-of-life care.

theory fits well with CBPR design because people are acknowledged as the "knowers of care."[20] People know what is best for their holistic health needs and can guide health care professionals about how to help them meet those needs.[20,21] The culture care theory and CBPR design also guided the development of the community-academic partnership.

METHODS

This study used a retrospective pretest-posttest quantitative survey to measure participants' knowledge about PEOLC and the cultural acceptability of the training intervention. Written qualitative data were also collected and analyzed for themes. The study was initially approved by the University of Tennessee, Knoxville, Institutional Review Board and, in subsequent renewal, was deemed exempt.

Study Procedures

A core group of community and academic partners, graduate and undergraduate nursing students, and other interested community members became trainers. An initial group training was held to practice presentation and engagement skills and critique one another. During each PEOLC training session, participants were asked whether they would be interested in becoming trainers; if so, they were trained by experienced trainers. Most trainers preferred to partner with another trainer to conduct PEOLC educational sessions. This approach provided an engaging format for participants and built confidence for trainers. In addition, trainers were encouraged to tailor the presentation format and content to fit the needs of the group and setting.

Trainers identified people/groups who wanted to know about PEOLC via word of mouth in their churches and communities and a local newspaper article. Interested persons were invited to a training session. Study participants were East Tennessee Appalachian adults who completed the PEOLC training. Exclusion criterion was inability to speak or read English.

Training sessions were conducted at 8 sites: a senior center, a rural hospital, a senior high rise, churches before and after worship services, Sunday School classes, and in-home Bible study groups. Church denominations represented were Presbyterian, United Methodist, Baptist, and nondenominational. At the end of training, participants were invited to take part in the study by completing a retrospective pretest-posttest evaluation (training evaluation form available upon request). Research demonstrates that participants' perceptions of knowledge before training exposure are often inflated, and measuring the change between pretest and posttest scores is not indicative of learning.[22] A more effective approach is to ask participants after the training to reflect on how much they knew about the topic before and how much they now know as well as how much they feel they learned from the training.[22]

Measures

The retrospective pretest-posttest evaluation tool was developed by education evaluation experts in collaboration with community-academic partners. The survey items are described hereinafter and shown in Tables 1 and 2. Content validity was established by 3 content experts.

Training Acceptability

Participants were presented with a series of statements (5) to ascertain how acceptable the training was to their cultural and spiritual beliefs. Statements referred to the participants' personal beliefs, the beliefs of their family and neighbors, and the beliefs of their religion or spiritual traditions. Participants also rated whether they would consider using end-of-life care for a family member or themselves should they need it. Responses to these questions were on a 5-point Likert scale with responses that ranged from 1 (strongly disagree) to 5 (strongly agree). The Cronbach α of this instrument for this sample was 0.884.

TABLE 1 Training Acceptability

Question	N	Mean ± SD
This training and its materials fits with my beliefs and values.	64	4.44 ± 0.92
This training and its materials fits with the values and beliefs of my family.	62	4.52 ± 0.80
This training and its materials fits with the values and beliefs of my neighbors.	62	4.31 ± 0.78
This training and its materials would fit with my religious/spiritual tradition.	63	4.54 ± 0.79
Based on the information in this training, I would consider using end-of-life care options if my family members or I needed such care.	63	4.62 ± 0.92

Rating scale: 1, strongly disagree; 2, disagree; 3, neutral; 4, agree; and 5, strongly agree.

Training Materials

Participants were given a series of statements (5) to evaluate whether the training materials were helpful and appealing. Items referenced were the brochure, slides, and video clips. Participants also rated the usefulness of the training. Answers were given on a 5-point Likert scale in which responses ranged from 1 (strongly disagree) to 5 (strongly agree). The Cronbach α for this instrument in this sample was 0.920.

Training Effectiveness

Participants were asked to rate their knowledge regarding the topics included in the training. Topics covered (5) were as follows: (*a*) what end-of-life care is; (*b*) how end-of-life care can support people, family, and friends; (*c*) what palliative care is; (*d*) what hospice care is; and (*e*) ways participants could help others facing end-of-life challenges. Knowledge level was ranked for both before the training and after the training. Rankings were given on a 4-point Likert scale using a scale of 1 (nothing) to 4 (a whole lot). The Cronbach α for this sample was 0.883.

Qualitative questions were included on the evaluation form. The questions were as follows: What did you like most about this training? What didn't you like? What would make this training better? As a result of this training, I would be comfortable helping a fellow church member, family member or neighbor by__. What would you like to share about this training?

Demographic Data

Demographic data such as age, sex, and race were collected using self-report on the survey form. Participants were also asked whether they had ever cared for a family member or friend at the end of life and whether they had

TABLE 2 Training Effectiveness

Question	N	Mean	SD	*P*
What end of life care is—before training	63	2.43	0.73	<.001
What end of life care is—after training		3.57	0.53	
How end of life care can support people, family, and friends—before training	66	2.59	1.47	<.001
How end of life care can support people, family, and friends—after training		3.90	1.22	
What palliative care is—before training	61	1.72	0.86	<.001
What palliative care is—after training		3.50	0.62	
What hospice care is—before training	62	2.69	0.80	<.001
What hospice care is—after training		3.97	0.45	
Ways I can help others dealing with end of life—before training	61	2.31	0.79	<.001
Ways I can help others dealing with end of life—after training		3.54	0.56	

Rating scale: 1, strongly disagree; 2, disagree; 3, neutral; 4, agree; and 5, strongly agree.

a personal advanced directive before they attended the training session.

Data Analysis

Demographic variables were described using frequencies, means, and standard deviations as appropriate to the level of measurement. Knowledge scores were developed for each item by creating a mean of the responses given. Knowledge before and after the training was compared using paired samples *t* tests. All data available were used in the analysis, which resulted in varying sample sizes. Analyses were performed in SPSS version 27. An a priori *P* value of .05 was set.

Short-answer qualitative data were categorized in an Excel spreadsheet according to each question on the evaluation form. Content analysis was used to identify prominent concepts or themes for each question.[23] Participant feedback was reported using short direct quotes. Two authors conducted content analysis, and a third author reviewed for accuracy.[24]

RESULTS

Demographics

In this sample of 66 people, 5.4% were between the ages of 18 and 35 years, 26.8% were 35 to 55 years old, 42.9% were 55 to 75 years old, and 25% were 75 years and older. Sex was predominantly female (61.9%), and most were White (74.2%). Most participants identified their occupation as a professional (65.1%), such as a teacher or health care worker. Of the participants, 71.4% had cared for a family member or friend at the end of life. A little over half (52.5%) did not have an advanced directive or living will at the start of the training.

Training Acceptability

Ratings for cultural acceptability for the training were high, indicating good acceptability. The material fit with the beliefs and values of the participant, the values and beliefs of the participant's family, the values and beliefs of neighbors, and the participant's religious/spiritual tradition. On the basis of the information in the training, overall, participants would consider using end-of-life care if their family members or they themselves needed it (see Table 1).

Qualitatively, participants shared what they liked most: "layman's terms, hearing real examples, open discussion format, interactivity, being informal, and the presentation." When asked what they did not like, many participants left the question blank. One participant stated "needed more time," and two "liked it all." There were few suggestions to make training better. Two individuals suggested "more men" be included and larger groups, and 1 person shared the "instructor talk more and others less."

Training Materials

Ratings for the materials used in this training were also high. Overall, participants found the brochure to be useful to take home and share with others. The slides were both interesting (mean, 4.25 ± 0.76) and helped the participants understand the information (mean, 4.33 ± 0.76). Participants also agreed that the video clips helped them understand the material (mean, 4.15 ± 0.90). Overall, the participants also rated the usefulness of the training as high (mean, 4.5 ± 0.71). Qualitatively, participants shared what they liked most: "the small group set up worked well to facilitate sharing," "sharing and learning county resources," and "paperwork passed out." Participants provided positive feedback about nursing students as trainers; for example, 1 person stated, "young people. They're great."

Training Effectiveness

Knowledge rankings across all categories showed significant improvement after the training. Participants felt they gained knowledge in what end-of-life care is ($P \leq .001$); how end-of-life care can support people, family, and friends ($P \leq .001$); what palliative care is ($P \leq .001$); what hospice care is ($P \leq .001$); and ways they could help others dealing with the end of life ($P \leq .001$). Overall, participants gained PEOLC knowledge from this training (see Table 2).

As a result of this training, participants qualitatively shared how they would help a fellow church member, family member, or neighbor (see Figure 2). Overall, participants shared the training "touched my heart," "very informative," "more people need to be aware of EOL decisions-education like this," and "it helped me to be more helpful."

DISCUSSION

This study demonstrated the feasibility and cultural acceptability of a training intervention to increase rural Appalachian persons' knowledge about PEOLC. Using TTT educational materials co-developed by community-academic partners and delivered by "trusted locals" was an effective model to engage and teach participants. Previous evidence also demonstrated that TTT is a useful health education tool and format for sustained community-based education.[13-15] Similar to this study, Guerrero et al[15] described the effectiveness of using low-literacy educational materials such as slides, a brochure, and handouts. In addition, the findings of this study and previous literature suggest that videos may improve health literacy challenges.[9,13]

Study findings indicated that the intervention was culturally and theologically acceptable to participants. Other studies also found the importance of tailoring interventions that reflect people's values and beliefs to promote health and improve access to health care.[13,16-19]

FIGURE 2. Participant actions to help family/community member/neighbor experiencing palliative and end-of-life care.

However, studies with community members as both trainers and co-developers of culturally acceptable training materials and methods were not found. For example, 1 study used church navigators to facilitate use of standardized evidence-based intervention materials that could be customized with local church and community pictures.[18] In another study, community churches had flexibility related to various aspects of intervention implementation but were expected to use several predeveloped educational materials.[13] In this study, guided by the culture care theoretical framework[20] and CBPR design,[21] community member expertise, collaboration, co-creation, and distinctive trainer style were integrated into every stage of the project and formed the bedrock of cultural acceptability and feasibility. Therefore, this study makes a unique contribution to the literature and provides an exemplar for future work aimed at developing culturally acceptable health education interventions.

A significant finding was that participants would consider using PEOLC for themselves or family members and were able to share how they would help a church member, family member, or neighbor experiencing PEOLC challenges. Similarly, in several studies using community faith-based initiatives and emphasizing the cultural values and beliefs of participants, researchers found that interventions also impacted families and communities.[16,24] Palliative and end-of-life care educational interventions could dismantle palliative and hospice myths and prepare people to access care earlier in the illness/dying trajectory and thus benefit from the full scope of palliative and hospice care.

Consistent with the findings of this study and others, churches can be effective locations for implementing health-promotion interventions. These faith-based spaces offer (1) meeting space where spiritual needs can be addressed and (2) social support and trusted relationships and (3) can promote participation and program sustainability.[13,16,17,19] In addition, faith-based settings can provide a space for end-of-life care decision making within spiritual values and beliefs and scriptural context as appropriate.[20] For further consideration, McDonnell et al[19] noted that members of faith-based organizations may "respond more favorably to information that does not seek to change core beliefs and…that include[s] spiritual and Biblical references rather than biomedical expert recommendations."(p7)

There is a national call to integrate culturally appropriate PEOLC into nursing curricula.[25,26] Community partners from this project were well positioned to teach students from their own unique knowledge and experiences, thus enriching nursing education. Nursing students at the university valued community partner training and used materials to train older adults at a local senior high rise. Experiences shared by community members were integrated (with permission) into a rural Appalachian end-of-life care simulation used with graduating seniors every year. This model could be integrated into nursing curricula at other schools and demonstrates the usefulness of local/regional

community partnership to co-create culturally appropriate PEOLC scenarios. Students and nurses must recognize that health can only be optimized in partnership with individuals, families, and communities in a culturally congruent manner.[13,16,17,19,20]

Limitations

Because this was a feasibility study, only a small sample size was recruited, and therefore, findings have limited generalizability. The sample was predominately White with several African American and 1 Hispanic participant. However, the sample is similar to racial demographics for the regional population.[8] When trainings were associated with faith-based communities, all were churches of Christian faith. Although this homogeneity is a limitation, a strength was that the intervention was used across multiple denominations in Appalachia and found to be culturally and theologically acceptable.

Future Research

This feasibility study was conducted with Appalachians in East Tennessee. Future research could be conducted in other regions of the United States and with larger samples. Training materials would need to be co-developed through community-academic partnerships that reflect the unique cultural values and beliefs of the region under study.

Lessons Learned

The project began using a truly community-based participatory focus. As the project and research evolved, partners used a collaborative, flexible, and open-minded approach to accomplish project goals. Community-academic partner expertise was essential. Each person, organization, or community shared unique knowledge and resources that were leveraged to create feasible and culturally acceptable PEOLC training.

Each member of the community-academic partnership had a personal PEOLC story that inspired passion about and commitment to the project. Partners shared their personal, professional, and/or community and faith-based knowledge that created a legacy to help others. In keeping with the cultural values and beliefs of these community partners, meetings began with a prayer led by a community member; God was sought to guide the project and fulfill needs.

Partners and participants were impacted by the project and discovered that each is on a journey. Partners found the work to be significant, rewarding, and missional. The project took a greater time commitment than originally expected. Throughout the years of working together, partners shared life's joys, challenges, and sorrows; several used PEOLC services and said goodbye to loved ones. The authors' advice to other communities and researchers is to allow CBPR projects to develop organically from partner expertise and regional cultural values and beliefs. Finally, and most importantly, intentionally place the community first.

CONCLUSION

Guided by the culture care theory and CBPR design, community-academic partners collaborated throughout the project, intervention, and research. Using TTT educational materials co-developed by partners and delivered by "trusted locals" was an effective model to engage and teach participants. Study findings demonstrate that the training intervention was feasible, culturally acceptable, and effective for increasing East Tennessee Appalachian persons' knowledge about PEOLC. Community member expertise/collaboration integrated into every stage of the project is the bedrock of cultural acceptability and feasibility. The work is being sustained in Appalachian counties, churches, communities, and organizations throughout the region. Nurses and interdisciplinary PEOLC professionals can use this intervention in the United States and other countries. As demonstrated by this project, training interventions and educational materials should reflect local cultural values and beliefs and is best accomplished by working in partnership with community members.

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- You'll need to create an account (it's free!) and log in to access My Planner before taking online tests. Your planner will keep track of all your Lippincott Professional Development online NCPD activities for you.
- There's only one correct answer for each question. A passing score for this test is 8 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.
- Registration deadline is March 6, 2026.

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DISCLOSURE STATEMENT

The authors and planners have disclosed that they have no financial relationships related to this article.