Development of the Blackfeet Community Hospice Project: Pilot Workshop

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Abstract

Taboo perception on talking about death and dying among American Indians/Alaska Natives is prevalent. This suppressive value makes hospice introduction difficult, leading hospice disparity. Working together by using a community-based participatory research approach over a decade, we conducted a 6-hour workshop including information sharing and group activities. The purpose of the study was to investigate the community readiness for end-of-life knowledge by conducting a public workshop. We used pre- and post-workshop surveys with Likert-type responses to five questions to assess the effect of workshop in end-of-life knowledge. Thirty individuals participated the workshop; 80% of them reported their knowledge increase on at least one question. While the survey had concerns, positive participant responses indicated readiness and appropriateness to use workshops to increase end-of-life knowledge.

Keywords: American Indians/Alaska Natives, end-of-life, hospice, qualitative study, workshop

Introduction: Higher premature death rates and lower hospice use have been identified as health disparities among American Indians/Alaska Natives (AIs/ANs). Since hospice care is considered as a gold standard to alleviate suffering, maintain dignity, and increase quality of life, several researchers identified and addressed the multifaceted causes of hospice disparity. The intervention taken most was to educate healthcare providers to be culturally attuned,[1-5] but less approach was taken directly to the AI/AN patients and their family mainly due to their taboo perception on talking about death and dying.[6] Locally on the Blackfeet Reservation, only two patients used a named hospice room in a nursing home in four years, and a hospital room that accommodates end-of-life (EOL) care needs is called the "death room."[7] Traditionally, Blackfeet people believe that elders should be taken care of at home, an expression of death may trigger two more deaths due to power of words, and silence soothes evil spirits that cause harm. These beliefs encourage the members to not discuss on death and dying. Breaking through this barrier to introduce a hospice option has been challenging. Several past attempts were temporary and unable to move forward. Nonetheless, the perception of some members appeared to be changing. The result of a 2017 EOL survey indicated that 76% of the respondents (70 out of 92) felt comfortable talking about death.[8]

Purpose: Spur on the community readiness for EOL knowledge by conducting a public workshop on the Blackfeet Reservation and assess its appropriateness and feasibility.

Method: The advisory committee (AC), consisting of the Blackfeet members and an academic nurse researcher, has been working together using a community-based participatory research approach since 2007 to introduce a hospice option for better quality EOL. We secured funding through approval and support on the project by the Blackfeet Nation with the resolution. Thus, we were told that IRB approval was not necessary and conducted a 6-hour public workshop including two meals at the senior center on the Reservation. This activity was a strong desire of the community partner with education background (the second author) from the partnership conception supported by public health approach. The pre- and post-workshop surveys were used to assess changes in knowledge.

Population: Recruited through posters and word of mouth, 30 individuals participated in the workshop; monetary incentive of $20 was offered. No demographic data were collected due to the participant's possible perception of a confidentiality threat.

Procedure: The AC decided the workshop topics to include: What is Hospice?; How Hospice works?—A cultural perspective; A Physician's Perspective on Hospice; Death and Dying a Blackfeet Perspective; Two Testimonies on with/without Hospice services; and Group Activities. The community partner (the second author) organized the logistics of workshop and invited presenters as well as seasonal AC members including a medical doctor and a registered nurse from the Indian Health Service and a community college faculty who had worked at a hospice center in the past. Based on the topics and content, the results of the previous survey, hospice being a sensitive topic, community of oral tradition, and the AC's strong request on survey to be short, the first author drafted one-page simple survey (i.e., 5 topics with 5 choices of responses each) to examine the participant's confidence level of knowledge and their comfort level of sharing with others. Development of a measuring tool was secondary because our primary purpose was to assess the community readiness for EOL knowledge through workshop. Then several AC members pre-tested and replaced one question from finance of hospice to access to hospice care services after prioritizing. These questions were self-assessment of knowledge levels in terms of a dying process, hospice, hospice services, access to hospice care services, and hospice volunteer and training. Survey responses included five Likert-type statements such as "1. I know the topic well and I can explain to others," 2. I know but difficult to explain, 3. I somewhat know, 4. I do not know, and "5. I do not want to talk about" or "5. I think the topic is useless." Starting with an explanation of the project history, the workshop included presentations with Q&A and group activities.

Results: Due to snow, two testimonial presenters were absent. However, the AC members pitched in. All 30 participants responded to the pre-workshop survey, and 90% (n=27) responded to every post-workshop survey question. The number of questions missed by the 3 participants were 5, 4, and 1. Additionally, all questions had one multiple-response each in either pre- or post-survey by 4 participants (One selected multiple responses twice). Among them, 4 multiple-responses were marked in-between numbers. The 5th multiple-response was marked 2 & 5 about a dying process, indicating that the individual knew the process which is difficult to explain to others as well as did not want to talk about dying.

In the pre-workshop survey, 18 participants (60%) reported not knowing how to access hospice services, and 19 participants (63%) did not know what hospice volunteer work is. In comparison, 24 individuals (80%) reported their knowledge increase in score after the workshop on at least one question while 4 participants did not report their knowledge increase in score, besides 2 participants who did not respond to more than 4 questions in post-workshop survey. Further, there were 11 responses of decreasing score in knowledge.

Table 1 indicates mean scores from Pre- and Post-Tests and p-value from paired t-test comparing pre- and post-scores. Except the topic of dying process, the participants significantly increased EOL knowledge in other four topics.

Eight individuals filled in the narrative comments that expressed appreciation and further support of holding the public workshop for EOL care and knowledge. The AC members' observations on the workshop that included active interactions between presenters and audience supported appropriateness to conduct the workshop and increase knowledge on EOL care as well.

Discussion: It has been tough for us to pursue the hospice project mainly due to the traditional taboo perception on the Reservation. In the past study, participants agreed with the importance of hospice option once they understood it correctly,[9] but we had not felt buy-in collectively for a long time. An effective intervention in AI/AN hospice disparity has not been found in literature. A gap appeared un-closable between those who promote the hospice option and who shun the EOL topic. Finally, our team decided to conduct the first workshop and approached to the public based on the Tribal motto—knowledge is power. We were more than happy to see 30 participants although a max of 40 was planned. It was a success to increase EOL knowledge of the participants within the budget ($2,000) and the timeframe (6 hours) although we will not know if new knowledge would be used/shared. We also do not know what contributed to the participants' attendance. It could include individual experiences related health and visibility of our team on the Reservation.

A possible explanation for the knowledge decrease in score is that the workshop provided a newfound awareness of what an individual did not know about a dying process, hospice, and/or hospice services. Concerns included attrition, some participant responses of knowledge decrease, and validity of the survey responses.

Conclusion: The AC meeting held later supported the idea of conducting similar workshops regularly and in new locations on the reservation. Suggestions to the future workshop include collecting data of reasons for the early leave, the self-assessment of decreased knowledge, and revising responses in the survey that should differentiate measuring a knowledge level from willingness to act. A person can be knowledgeable on hospice services but not want to talk about the subject. An addition of a focus group at the end of the workshop would assist to understand the phenomenon of how participants perceive hospice care. Rationalizing the intervention based on theories such as EOL care[10] and information seeking/sharing behavior will build up evidence and further contribute to alleviate the AI/AN hospice disparity.

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