

End-of-Life Care in American Indian Populations of the Southwest

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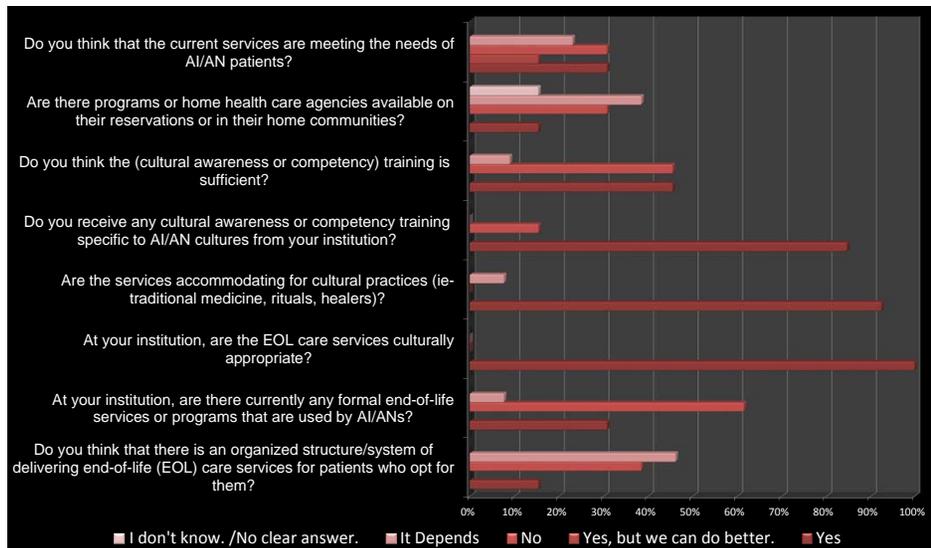
Abstract

As the American Indian/Alaskan Native (AI/AN) populations age and live longer with chronic disease as seen with the rest of the general population, the discussion of palliative care is becoming more important. The paucity of research serves as an impetus to learn and examine the need of available palliative care resources for the AI/AN populations. We present an analysis of thirteen interviews with staff members of local hospice organizations and hospitals in Phoenix, Arizona. We investigate the current needs, social and cultural barriers, and the infrastructure of how palliative care is accessed and delivered. The results show that there is likely an organized structure of how palliative care is delivered to AI patients, however under certain circumstances, such as location, the tribe, cultural belief differences, and a patient's tribal support and connection. These circumstances present challenges to creating a cohesive, comprehensive system. There is no overarching network. Current services accommodate individual patients as best as possible with the resources available. Due to vastness of diversity, it is impossible to learn about every tribe and its traditions. Specific areas for improvement included pain management, patient education about EOL care, financial support to develop formal services and programs, psychosocial support for patients, bereavement support, cultural awareness, provider education about EOL care, spiritual care, availability and access to care, networking among tribes, transition of care from hospital to home, travel between reservations and care facilities in cities, and advance directives planning. In conclusion, this pilot study shows the need for further research. There needs to be more communication between the IHS sites and local hospice care agencies. The absence of a network makes it more challenging for patients to navigate and find the care they need.

Methods

Interviewees were recruited from the Phoenix Indian Medical Center, and three hospices in Phoenix- The Crossing Hospice, Hospice of Arizona, and Hospice of the Valley (HOV). Thirteen interviewees participated. Participants were recruited by word of mouth, networking, and emailing contacts. There was no specific qualification that we were seeking in participants, other than they had to have had experience in participating in the delivery of palliative care to local American Indian populations. Participants' years of work experience ranged between 8 months and 32 years. Their roles included a chaplain, nurse, a nurse practitioner, community health educator, spiritual care coordinator, director of operations, medical social worker, a nurse case manager, physicians, and case managers. The interview was an open, inductive survey. It consisted a total of 14 questions, some of which included follow-up questions depending on the individual's answer. Questions fell under one of 4 themes: 1) existence of a current structure of delivery of palliative care and services, 2) cultural appropriateness of services and training, 3) comprehensiveness and availability of current EOL care, and 4) areas of need for improvement.

Results



Introduction

Palliative care is an important form of care that can provide patients with terminal illnesses and their family members clinical, physical, psychosocial, and spiritual support. Often, people seek palliative care very late in their care trajectory. If palliative care is initiated earlier, patients and family members may benefit more from the continuous care and emotional support that includes pain management, advance care planning, caregiver support, and bereavement services..

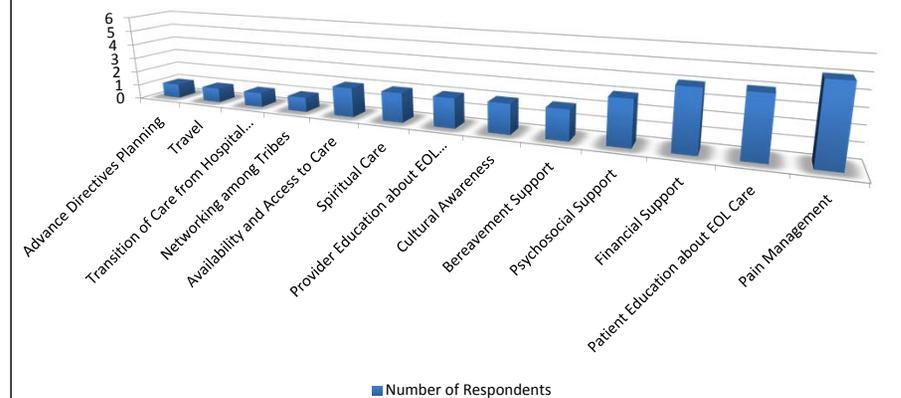
This project addresses these issues about palliative care for AI/AN populations: 1) Geographic availability of palliative care programs; 2) Whether existing palliative care services are meeting the needs of AI/AN patients and their families; 3) Whether any informal or formal overarching program policies and procedures in palliative care exist in Arizona; and, 4) The trajectory of palliative care planning for AI/AN patients. The goal is to create a plan of how to improve the palliative services for AI/AN patients and their families.

Discussion and Conclusions

An organized system exists in an infant stage in terms of delivering EOL care to American Indians in Phoenix. Multiple factors influence this structure, and there is no easy or quick solution to building a system that works effectively and efficiently for all populations. Multiple variables need to be addressed. PIMC has understood informal processes of triaging care. However, PIMC has very little information about how other institutions in the IHS operate. There needs to be an overarching network within IHS that links to outside operating hospices. Key recommendations based on the results of this study are to:

- Establish formal guidelines about palliative and hospice care for each institution.
- Create a palliative care team that specializes in handling that patient's care.
- Establish more care centers closer to or on reservations.
- Continue cultural competency learning, and request feedback from patients about quality of care.
- Request for resources and funding for comprehensive care and improvement of areas of concern, such as creating a pain management program or promoting education and awareness about palliative care.
- Conduct future research that will incorporate a larger sample size of providers, and begin to research patients' thoughts and opinions about palliative care.

Areas of Improvement



Acknowledgements

I wish to thank my mentor Drs. Michael H. Trujillo and Catherine Witte. I would also like to thank all the participants for volunteering and giving their time to this project, and the participating institutions- Phoenix Indian Medical Center, Hospice of the Valley, Hospice of Arizona, and The Crossing Hospice.