Hospice and Palliative Care in Indian Country

Life, death, and dignity are uniquely defined by one’s own culture.

- There are three tribal and one urban area program well known in Indian Country for offering culturally sensitive palliative and hospice care services.
- The program profiles here highlight certain program elements but focus on best practices; particularly in the areas of program successes and innovations, incorporating culture, funding, and lessons learned.
- There were several elements that were found overlap between these programs. These overlaps are outlined here as the best practices in offering hospice and palliative care in Indian Country.

Successes and Innovations

- All of the programs used an interdisciplinary team to provide care. These teams were made up of doctors, nurses, home-health aids, licensed nurse practitioners, and volunteers. Some programs also involved case managers, chaplains, social workers, artists and traditional healers.
- All of the programs profiled offer training to hospice staff on care provision, including cultural sensitivity.
- Programs felt that it was important that at least one staff member be fluent in the native language of the people served.
- Building partnerships and networking with other hospice and palliative care programs and providers as well as with other health providers, such as the Indian Health Service (IHS) was seen as important to program support.

University of New Mexico
Palliative Care Program

“We're looking to build a relationship with the patient and the family and having the providers be in a more humble situation where the providers ask the patient to educate them on their culture or tradition.”

-Venita Wolfe, MS, Education Specialist, Palliative Care Program

Tohono O’odham Hospice

“Culturally sensitive care is a learning curve that you are always on.”

-Dorothy Low, LPN, Administrator, Tohono O’odham Hospice
Best Practices in Culturally Sensitive End-of-Life Care
Summary of Program Best Practices

Incorporating Culture
- Programs felt that it was important to recognize that culturally sensitive care is fluid and should be individually based.
- Establishing trust with patients and the families was seen as paramount to providing good care.
- Programs recognize that the decision-making process for each family is critical, and means accommodating family meetings and including immediate and extended family within medical discussions.
- In order to discuss the process of passing on, programs took steps to use specific and culturally appropriate techniques, such as using a translator, third-person descriptions, or a tribal consult.

Funding
- Some programs engaged in cost sharing to help their funds go as far as possible. An example of this might be having the area IHS to supply durable medical equipment, while the servicing program covers medication and home visits.
- Tribes are also a good source for program support and may provide funding to help support palliative and hospice care for tribal members.
- Several programs got their start with seed money from grants, and then supported their programs through billing to Medicare, Medicaid, and/or private insurance.
- Programs must prepare for and be aware of the frequent changes in reimbursement policy at the state and federal levels and have a supplement plan in place.

Lessons Learned
- It is important to understand patient needs within the setting; whether it is a hospital, clinic, or nursing home.
- Having a champion that understands the program and can work it into the fabric of existing institutions can be vitally important.
- Staff should feel comfortable asking for clarification from patients and family in respectful ways.
- Staff should also understand that their work is more than medical; it is spiritual and emotional.