

Best Practices in Culturally Sensitive End-of-Life Care

Program Profile: Tohono O'odham Hospice

Tohono O'odham Nursing Care Authority – Tohono O'odham Hospice

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

- The Tohono O'odham Nation assembled an independent board tasked to develop a program for elders. The initial program opened in 2002 as a skilled nursing facility. Five years later, in 2007, a hospice program was developed.
- The Tohono O'odham Nation based the need for hospice care on the lack of end-of-life care in the immediate community and the non-tribal hospice's clear lack of understanding of cultural values.
- The development of the Tohono O'odham Hospice program was a community effort, with community and tribal council support.

Successes and Innovations

- The Tohono O'odham engage in regular and ongoing education and outreach to increase hospice awareness and provide insight into how hospice services benefit the community.
- Most hospice referrals come from community member recommendations and are based on their personal experiences.
- The program, tribal leadership, and wider community share in the commitment to provide a continuum of care for elders.
- Surveys, follow-up calls, and feedback from program referral sources are used to measure program success and progress.

Operated by: Tohono O'odham Nursing Care Authority

Established: 2007

Location: Sells, Arizona

Area served: Nine Districts of the Tohono O'odham Tribe

Contact Information: Dorothy Low, LPN, Administrator, (520) 383-1893

Website: <http://www.toltc.org/hospice.html>

Mission Statement: To take a leadership role in providing a continuum of care and services designed to enhance the physical and intellectual qualities of life for aging O'odham and other members of the Nation in need of skilled nursing care.



Best Practices in Culturally Sensitive End-of-Life Care

Program Profile: Tohono O’odham Hospice

Incorporating Culture

- Use alternative terms to discuss the end of life, or describe it from another person’s perspective.
- Avoid definitive language, terms, or timelines.
- Recognize and accommodate the decision-making process for families seeking hospice care.
- Incorporate patient and family beliefs and values, such as the use of traditional healers and religion.

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

-Dorothy Low, LPN,
Tohono O’odham Hospice

Administration, Staffing & Facility

Tohono O’odham’s palliative care and hospice staff includes one registered nurse, one CNA, one part-time social worker, and occasional volunteers. Currently serving about two patients, the program strongly believes in the importance of always having Tohono O’odham language speakers on staff.

Funding

- The hospice program is Medicare certified.
- Program funding is supported by seed money invested by the nursing home from a tribal subsidy, which helps support tribal members who are unable to pay for hospice services and are ineligible for Medicare.
- Housed under the nursing home umbrella of service, funding to the hospice program is allocated through the nursing home budget.
- The nursing home is eligible to receive a tribal subsidy to help provide services.
- Symptom management in late-stage disease processes can be reimbursed under home care and can provide opportunities for discussion around care goals.

Lessons Learned

- Sometimes, a lag exists between program start-up and establishing a steady funding stream.
- Be prepared to change funding streams. Stay flexible while finding funding to support programming. Tribal funds may be necessary for success.

Future Directions

Tohono O’odham’s next steps for improving the quality of end-of-life care include:

- Providing responsive care by having conversations with patients and families before hospice is imminently needed,
- Providing consultation to off-reservation entities about traditional healing and cultural traditions, and
- Pursuing the possible creation of a home health care service.