



Department of Health & Human Services, Centers for Medicare & Medicaid Services

# **LTSS Research: Hospice in Indian Country**

Literature Review

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### Background

Hospice and palliative care provide comfort for patients with chronic or terminal illness who are nearing the end of life. Hospice is usually offered to patients who are no longer seeking a cure for their illness and who have a life expectancy of 6 months or less. Palliative care may be provided to patients who are seeking curative treatment. Both types of care focus on preserving patients' quality of life through symptom management and pain relief, as well as emotional, social, spiritual, and end-of-life planning support.<sup>1</sup>

A 2014 literature review by the Centers for Medicare & Medicaid Services (CMS) examined the use of hospice and palliative care services by American Indians and Alaska Natives (AI/ANs).<sup>2</sup> The report identified significant barriers that complicate the delivery of compassionate, culturally appropriate end-of-life care to AI/AN patients. These barriers included:

- a low number of tribally operated hospice and palliative care programs,
- difficulty accessing care due to geographic remoteness,
- disparate access to health insurance, and
- low levels of cultural sensitivity among care providers.

Recent research underscores the need to address these barriers, in part, by infusing cultural traditions and values into end-of-life care for AI/AN patients. This research is summarized in the sections below.

### Barriers to End-of-Life Care for AI/ANs

The AI/AN elder population, aged 65 and older, is projected to quadruple by 2060.<sup>3</sup> This rapid growth has raised concern for care providers throughout Indian Country about the myriad of health disparities and hurdles elders currently face, including access to end-of-life care services, culturally responsive services, and community awareness about end-of-life care.

The low number of tribally run and Indian Health Service- (IHS) operated hospice programs<sup>4</sup> can inhibit AI/AN patients' access to end-of-life care. Along with this limited number of programs, tribes face many other challenges in their efforts to implement hospice care programs, including insufficient funds and a lack of infrastructure.<sup>5</sup> These challenges, detailed below, exist across reservation, rural, and urban settings.

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<sup>1</sup> Sopcheck 2016, CMS 2014

<sup>2</sup> CMS 2014

<sup>3</sup> Boccuti et al. 2014

<sup>4</sup> Cherokee Hospice Care (Cherokee Nation), and Tohono O'odham Nursing Care Authority-Tohono O'odham Hospice (Tohono O'odham Tribe) are the two known tribally operated hospice programs. University of New Mexico-Palliative Care program provides culturally sensitive palliative care planning.

<sup>5</sup> Isaacson et al. 2014



- *Reservation settings* – The unavailability of care providers on or near reservations may factor significantly into lower use of hospice care among AI/AN patients. This leaves families and patients seeking end-of-life care to turn to off-reservation programs and services, or not seeking out these services.
- *Urban settings* – About 60% of AI/AN elders reside in urban areas. These elders have limited access to IHS facilities or tribal programs and services. For this reason, many urban AI/ANs must seek end-of-life care from non-tribal providers.<sup>6</sup>
- *Rural settings* – About 40% of AI/AN elders live in rural settings. For many patients, especially those living in remote areas, transportation challenges, such as long travel distances and commuting expenses, hinder access to end-of-life care services.<sup>7</sup>

Barriers to end-of-life care extend beyond the patients' locations. Among end-of-life care programs that serve AI/AN patients in the Southwest, a recent study found that a lack of formal policies and guidelines and the absence of educational resources for end-of-life care often disrupt organized care delivery.<sup>8</sup> A recent analysis from the University of Arizona on AI/AN views of health care systems that serve AI/AN populations described how discussions of death or illness can go against cultural norms, and AI/AN patients fear they will face negative outcomes if they have these discussions. In some tribal cultures, patients may decide not to participate in health screenings for fear of being diagnosed with a terminal illness. Harris et al recommended culturally sensitive, community-wide education about cancer and end-of-life care to increase screening rates and hospice use.<sup>9</sup>

The health disparities listed below for AI/AN patients with cancer and higher rates of rurality exemplify some of the barriers AI/AN patients face.

- AI/AN patients have a higher cancer-related mortality rate than that of Caucasians, and their mortality rate has increased over the past 20 years.<sup>10</sup>
- AI/AN patients experience poorer outcomes following cancer diagnoses,<sup>11</sup> increasing the likelihood that they will need hospice or palliative care.<sup>12</sup>
- Despite this increased need, AI/AN patients are less likely to seek hospice care than Caucasian patients.<sup>13</sup>

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<sup>6</sup> Boccuti et al. 2014

<sup>7</sup> Harris et al. 2016

<sup>8</sup> Law 2015

<sup>9</sup> Harris et al. 2016

<sup>10</sup> Shiovitz et al. 2015

<sup>11</sup> Guadagnolo et al. 2016

<sup>12</sup> Gebauer et al. 2016

<sup>13</sup> Guadagnolo et al. 2016; Shiovitz et al. 2015



Barriers to appropriate care, including limited access to health care facilities, low rates of health screenings, and late diagnoses, may contribute to this trend, though a high number of AI/AN elders have insurance or access to medical benefits.<sup>14</sup> Most AI/AN elders (96%) have Medicare coverage, 24% have supplemental coverage under Medicare savings programs or Medicaid, and nearly half (48%) have private insurance or access to Veterans' benefits.<sup>15</sup>

Some AI/AN cultures have a deeply ingrained aversion to talking about terminal illness and death, which may complicate communication between providers and AI/AN patients about end-of-life care needs, creating another barrier for AI/AN patients seeking care. Although views of death and willingness to discuss it vary across tribes, communities, and individuals, some providers may assume that all AI/ANs prefer to avoid these topics.<sup>16</sup> To honor cultural diversity across tribes, providers may need to engage in ongoing cultural sensitivity training that accounts for differences among regions, tribes, and individuals.<sup>17</sup> Considerations for AI/AN cultures and values, described in the next section, may help caregivers and providers reduce some of the barriers faced by AI/AN patients.

### Culture and Values

Honoring cultural values and traditions is a key step caregivers and providers can take to reduce barriers to hospice care in Indian Country.<sup>18</sup> The 2014 CMS literature review of hospice care in Indian Country highlights a low level of cultural sensitivity among care providers as a significant barrier to end-of-life care.<sup>19</sup> The sections below explore recent research that reiterates the finding from the 2014 CMS literature review on the importance of incorporating the following cultural considerations into end-of-life care delivery:

- Cultural sensitivity among hospice care facilities, providers, and caregivers;
- Communication between providers and patients about end-of-life care; and
- Integration of tradition, family, and spirituality into end-of-life care.

### Hospice Care Providers

A study of non-tribally operated hospice programs in Arizona, where a high population of AI/ANs reside, found that many facilities that provide hospice care to AI/AN patients lack formal, organized care delivery systems. While many caregivers reported receiving cultural sensitivity training related to AI/AN cultures, such trainings often failed to specifically cover end-of-life care for this population.<sup>20</sup> Similarly, a

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<sup>14</sup> Sawchuk et al. 2016

<sup>15</sup> Boccuti et al. 2014

<sup>16</sup> Gebauer et al. 2016

<sup>17</sup> Law 2015

<sup>18</sup> Guadagnolo 2015

<sup>19</sup> Centers for Medicare & Medicaid Services 2014

<sup>20</sup> Law 2015



study of end-of-life care programs on American Indian reservations in South Dakota, which also has a high AI/AN population, found that fewer than half of the programs had designated points of contact for inquiries about hospice and palliative care. Further, most of these facilities did not offer palliative care training to staff.<sup>21</sup>

### Cultural Sensitivity Training

Research links the integration of cultural considerations in provider and caregiver training to increased confidence in their ability to provide culturally sensitive care.<sup>22</sup> To be most effective, cultural sensitivity training for care providers and caregivers should be ongoing and established for a variety of care providers and caregivers.<sup>23</sup> Specifically, because of their proximity to patients and their likelihood to provide compassionate care, nurses are an especially important audience for culturally sensitive end-of-life care trainings.<sup>24</sup> In addition to cultural sensitivity training for care providers and caregivers, training local health educators, family caregivers, and the entire community about hospice is a key step toward increasing AI/AN elders' use of hospice care.<sup>25</sup>

### Family Caregivers

Often in tribal communities, family members become primary caregivers for terminally ill loved ones who need support with daily living activities. However, a recent examination of the resources available to family caregivers found that they often lack sufficient information and training on providing effective end-of-life care. Further, family caregivers do not often seek hospice care for their loved ones, commonly due to a lack of awareness or their negative impressions of hospice services.<sup>26</sup>

### Communication Between Providers and Patients

AI/AN elders may face barriers related to cross-cultural communication when seeking end-of-life care. Research suggests that care providers may be less likely to fully explain end-of-life care options to patients of cultural or ethnic backgrounds that differ from their own.<sup>27</sup> False assumptions about AI/AN communities universally viewing death as a taboo topic may further discourage providers from appropriately discussing end-of-life care with them.<sup>28</sup> Illness and death may be taboo topics in some AI/AN communities, but communication preferences about these topics vary among tribes,

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<sup>21</sup> Isaacson et al. 2014

<sup>22</sup> Martin & Barkley 2016

<sup>23</sup> Law 2015

<sup>24</sup> Sopcheck 2016

<sup>25</sup> Colclough & Brown 2014

<sup>26</sup> Colclough & Brown 2014

<sup>27</sup> Martin & Barkley 2016

<sup>30</sup> Martin & Barkley 2016



communities, and individuals.<sup>29</sup> Further, avoidance of these topics does not mean a patient opposes pain treatment or other measures of comfort.<sup>30</sup>

Language barriers and the effects of historical trauma on a patient's view of health care systems are additional considerations providers must include in conversations about end-of-life care. For some AI/AN patients, language barriers complicate communication with health care providers. Even patients who speak English may prefer to hear concepts explained in their Native languages.<sup>31</sup> Professional interpreters can present care options to patients in respectful, clear language and help the patients articulate their wishes and priorities for end-of-life care.<sup>32</sup> Distrust of health care systems rooted in historical trauma may also deter AI/AN elders from seeking end-of-life care. Improved access to culturally appropriate hospice care is crucial to reducing distrust and encouraging use of hospice care.<sup>33</sup>

### Honoring Tradition in Treatment

Culturally sensitive end-of-life care for AI/AN patients must involve efforts to preserve quality of life across all areas of their lives, including family, spirituality, and cultural traditions. Fully informing the patients and their family members about the diagnosis and treatment options promotes acceptance and healthy coping. Incorporating tradition and spirituality into treatment helps further support patients and their families during this difficult time.<sup>34</sup> Research links the inclusion of spiritual support in end-of-life treatment to a higher quality of life among patients.<sup>35</sup>

The Palliative Care Consultation Service at the University of New Mexico has successfully incorporated culture and tradition into care delivery and can serve as a model for other end-of-life programs that serve AI/AN patients. This culturally tailored program integrates traditional healing and culturally sensitive communication approaches into end-of-life care.<sup>36</sup>

### Recommendations

This literature review builds on the 2014 CMS examination of hospice care in Indian Country, which recommended the following ways to minimize barriers to compassionate, culturally appropriate end-of-life care options for AI/AN patients.

1. Gain support from tribal leadership, program staff, and the community for palliative and end-of-life care provisions.

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<sup>30</sup> Martin & Barkley 2016

<sup>30</sup> Martin & Barkley 2016

<sup>31</sup> Gebauer 2016

<sup>32</sup> Martin & Barkley 2016, Gebauer 2016

<sup>33</sup> Guadagnolo et al. 2015

<sup>34</sup> Colclough & Brown 2014

<sup>35</sup> Martin & Barkley 2016

<sup>36</sup> Guadagnolo et al. 2015



2. Create partnerships with national and local entities to help build effective hospice care programs.
3. Embed tribal consultation into programs to allow for more seamless cultural integration.
4. Develop a cultural sensitivity training curriculum for new and existing health care workers.
5. Build flexible programs to adjust to patients' needs and personnel shortages.
6. Establish trust between patients and health care providers.
7. Educate patients and families about the purpose and benefits of hospice care.<sup>37</sup>

The more recent research explored in this literature review reiterates the importance of leveraging partnerships to help build effective hospice care programs, providing cultural sensitivity training for providers and caregivers, and educating patients and families about hospice care with additional recommendations as follows.

1. Broaden nurses' understanding of end-of-life care for AI/AN patients related to hospice care policies and options.<sup>38</sup>
2. Include family, spirituality, and cultural traditions in end-of-life care.<sup>39</sup>
3. Involve the community and engage with elders and other key community members to successfully implement hospice services.<sup>40</sup>
4. Raise community awareness about hospice care to increase trust in health care systems and understanding about hospice care among communities, family caregivers, and those who may need end-of-life care.<sup>41</sup>
5. Focus on resolving socioeconomic barriers to seeking hospice care, such as transportation challenges.<sup>42</sup>
6. Provide integrated, ongoing cultural sensitivity training for care providers and caregivers. To honor cultural elements in caring for AI/AN patients, recent research suggests that providers do the following.
  - Inquire about individual preferences, values, and beliefs related to end-of-life care.
  - Hire interpreters to reduce language barriers and develop materials that honor cultural preferences for end-of-life care discussions.
  - Present treatment options with and without medical components.
  - Evaluate and treat spiritual pain in collaboration with spiritual advisors.
  - Learn which services may be available to elders who live in rural settings before recommending specific treatments or services.

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<sup>37</sup> Centers for Medicare & Medicaid Services 2014

<sup>38</sup> Sopcheck 2016

<sup>39</sup> Martin & Barkley 2016, Colclough & Brown 2014

<sup>40</sup> Isaacson et al. 2014, Martin & Barkley 2016

<sup>41</sup> Isaacson et al. 2014

<sup>42</sup> Shiovitz et al. 2015



- Ask patients and families how they would like to receive information.
- Consider describing diagnoses and negative outcomes in third person if the patient views the direct discussion of illness and death as inappropriate.<sup>43</sup>

To connect the growing number of AI/AN elders with culturally appropriate hospice and palliative care, several barriers must be addressed. Significant barriers that prevent AI/AN elders from receiving end-of-life care include a low number of tribal or IHS-operated hospice programs, transportation challenges, and low levels of cultural sensitivity within non-tribal hospice programs. Community, partnership, and emphasis on culturally sensitive approaches to care remain key focal points in successfully providing compassionate hospice and palliative care in Indian Country.

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<sup>43</sup> Martin & Barkley 2016



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