

A Review of the Literature on Native Hawaiian End-of-Life Care: Implications for Research and Practice

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Abstract

The need for cultural understanding is particularly important in end-of-life (EOL) care planning as the use of EOL care in minority populations is disproportionately lower than those who identify as Caucasian. Data regarding the use of EOL care services by Native Hawaiians in Hawai'i and the United States is limited but expected to be similarly disproportionate as other minorities. In a population with a lower life expectancy and higher prevalence of deaths related to chronic diseases such as cardiovascular disease, diabetes, and obesity, as compared to the state of Hawai'i as a whole, our objective was to review the current literature to understand the usage and perceptions of EOL care planning in the Native Hawaiian population. We searched ten electronic databases and after additional screening, seven articles were relevant to our research purpose. We concluded that limited data exists regarding EOL care use specifically in Native Hawaiians. The available literature highlighted the importance of understanding family and religion influences, educating staff on culturally appropriate EOL care communication, and the need for more research on the topic. The paucity of data in EOL care and decision-making in Native Hawaiians is concerning and it is evident this topic needs more study. From national statistics it looks as though this is another health disparate area that needs to be addressed and is especially relevant when considering the rapid increase in seniors in our population.

Keywords

Hawaiian, End-of-Life

Abbreviations

AAPI = Asian-American and Pacific Islanders

EOL = End-of-Life

NHPI = Native Hawaiian and Pacific Islander

POLST = Physician Order for Life-Sustaining Treatment

NH = Native Hawaiian

Introduction

Cultural respect is necessary in providing quality healthcare and reducing health care disparities. The values, beliefs, and customs of diverse patients influence their views on illness, disease, health, wellness, and health care services. It is critical for health care professionals to understand and respect the culture and beliefs of patients in order to meet and respond to their needs in a culturally sensitive manner.¹ The need for cultural understanding is particularly important in end-of-life (EOL) care planning and is one of the domains listed in clinical practice guidelines for palliative care published by the National

Consensus Project for Quality Palliative Care.² According to the National Institute on Aging, EOL care is the term used to encompass medical care and support provided during the period surrounding death³ and may include palliative care, hospice, and usage of advanced directives and the Physician Order for Life-Sustaining Treatment (POLST) form.⁴

The use of EOL care in minority populations is disproportionately lower than those who identify as Caucasian, as seen in the 2016 data from the National Hospice and Palliative Care Organization in which 86.5% of Medicare hospice patients were Caucasian.⁵ Reasons for these differences between ethnic groups are unclear though EOL researchers have proposed possible contributing factors include religious or cultural differences, caregiver respect for patient autonomy, barriers to access, and knowledge of EOL care options.⁶

Data regarding the use of EOL care in American Indian/Alaska Native and indigenous Australians is limited.⁷⁻⁹ Similarly, data regarding the use of EOL care services by Native Hawaiians in Hawai'i and the United States is limited but expected to be similarly disproportionate as other minorities. In a population with a lower life expectancy and higher prevalence of deaths related to cardiometabolic diseases as compared to the state of Hawai'i as a whole,¹⁰ our objective was to review the current literature to understand the usage and perceptions of EOL care planning, including advanced care planning and palliative care, in the Native Hawaiian population.

Methods

Ten electronic databases were searched (Academic Search Complete, Alt HealthWatch, CINAHL with Full Text, Health Source—Consumer Edition, Health Source: Nursing/Academic Edition, Legal Collection, Legal Information Reference Center, MEDLINE, Psychology and Behavioral Sciences Collection, and Social Work Abstracts). MeSH search terms included “advanced directive,” “advanced care planning,” “end-of-life care,” “provider orders for life-sustaining treatment,” “palliative care” or “hospice,” and “Native Hawaiians” or “Hawaiians.” Articles were assessed for quantitative data regarding hospice, palliative care, POLST, or advanced directive utilization or qualitative data regarding influences on EOL care usage (eg, socioeconomic, cultural, religious, access, workforce development).

Results

Our methods revealed twenty articles. Articles were excluded for the following reasons: duplicate article, unrelated to Native Hawaiian population, or too general EOL care topic. After screening, seven articles were relevant to our research purpose. Six articles focused on populations including Native Hawaiians in Hawai‘i,¹¹⁻¹⁶ one article included Native Hawaiians in the larger Asian-American and Pacific Islanders (AAPI) population in the United States.¹⁷ The process of article selection is outlined in Figure 1.

Three articles had quantitative measures of EOL care use or preferences in patients. The first article, analyzing a nationwide database in the United States, found lower rates of hospice care in minority groups, including Native Hawaiian,¹⁷ while the two other articles based on data from Hawai‘i found increased or comparable rates to national estimates of advanced directive, living will, and/or hospice use.^{11,12}

Ngo-Metzer, et al,¹⁷ conducted a retrospective review of the last year of life of AAPI as well as white Medicare beneficiaries diagnosed with cancer and registered with the Surveillance, Epidemiology, and End Results Program. They found every ethnic subgroup of AAPI (Chinese, Japanese, Filipino, Hawaiian/Pacific Islander, and other Asians) studied had lower rates of hospice use than white patients after adjusting for patient demographic (sex, race or ethnicity, birthplace, marital status, residence in urban or rural area, median household income of ZIP code of residence, type of insurance) and clinical characteristics (stage at diagnosis and type of primary cancer).

Braun, et al,¹¹ added questions regarding advance directive completion and preference for in-home death and hospice in two state-wide telephone surveys (1998 Behavioral Risk Factor Surveillance System, 1999 OmniTrack health survey) in Hawai‘i and found living will and healthcare power of attorney completion rates of Native Hawaiian (22%) and Filipino (13%) in Hawai‘i were lower than those of local Japanese (34%), Chinese (36%), and Caucasian (36%) ancestry but comparable to national estimates (15%-25%). Of note, these results differed from the lower advanced directive completion rates experienced on the mainland among other minority Americans groups like African Americans and Hispanic Americans. They speculated higher completion rates by certain minority groups in Hawai‘i may be related to higher levels of income and education in local Japanese, Chinese, and Caucasians as compared to Filipino and Hawaiian groups. Higher respect for the medical field by Asian cultures may also have been a factor.

Fernandes, et al,¹² studied symptom relief, quality of life, resource utilization, and satisfaction with a home-based palliative care program offered at Kokua Kalihi Valley, a federally qualified community health center in urban Honolulu serving low-income, immigrant populations from Asia and the Pacific Islands. They

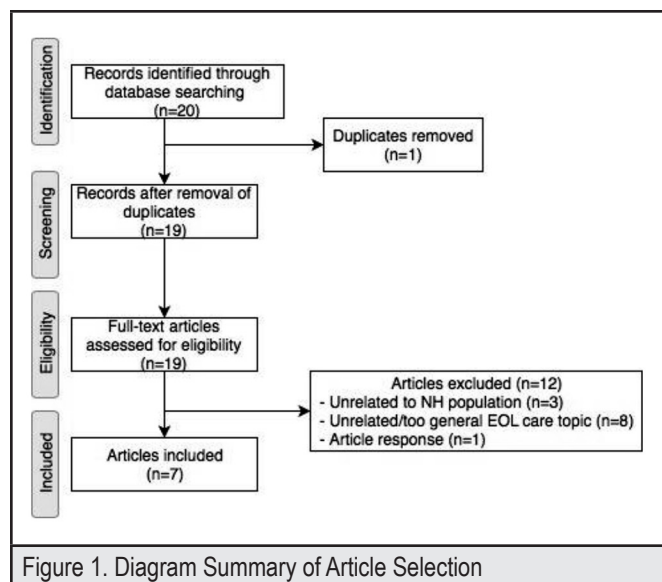


Figure 1. Diagram Summary of Article Selection

NH = Native Hawaiian

found an increased advanced directive completion rate (90%) and hospice enrollment for eligible patients (85%) in a group of patients in which all except one were a minority (including Samoan, Filipino, Japanese, Micronesian, Hawaiian). They attributed the increased rates, which differ from other research on minority Americans, to be related to the staff developing trusting relationships with patients and families, incorporating bilingual case managers to explain EOL concepts, and aiding with family-based decision-making when desired by patients.

The remainder of the articles discussed topics related to factors which may influence patient and family reception and understanding to EOL care services. There were three articles related to the development of a culturally knowledgeable workforce^{13,15,16} and one article regarding the role of the Christian church in EOL care.¹⁴

Three articles focused on the important role of cultural understanding by health professionals in order to improve communication with families.^{13,15,16} Anngela-Cole, et al,¹³ highlighted the complexities with providing EOL and palliative care services to the people from the Pacific Basin who come to Hawai‘i. They emphasized the importance of understanding how historical trauma and cultural beliefs regarding death impact patients’ and families in palliative care situations. Kataoka-Yahiro, et al,¹⁵ conducted focus groups with Asian and Native Hawaiian families in two nursing homes in Hawai‘i and found a need to improve culturally appropriate approaches and communication for palliative and EOL care services in these ethnic groups. Flavin¹⁶ studied pre- and post-test measures of a research-based Cross-Cultural Training program for their home care nurses, a majority who were white. This program aimed to educate about beliefs, values, and practices relating to illness and dying in Filipino, Hawaiian, Japanese, and gay-Caucasian groups. Although the results of the program were statistically

Table 1. Articles Reviewed: Native Hawaiian (NH) End-of-Life (EOL) Care				
Author(s), year	NH specific?	Design/Study	Location of study	Findings/recommendations
Ngo-Metzer, et al, 2008 ¹⁷	No – included within AAPI	Retrospective review	United States	Every ethnic subgroup of AAPI studied had lower rates of hospice use than white patients after adjusting for patient demographic and clinical characteristics.
Braun, et al, 2001 ¹¹	Yes	Quantitative, questions added to two state-wide surveys	Hawai'i (state-wide)	Living will and healthcare power of attorney completion rates of NH (22%) and Filipino (13%) in Hawai'i were lower than those of local Japanese (34%), Chinese (36%), and Caucasian (36%) ancestry but comparable to national estimates (15-25%).
Fernandes, et al, 2010 ¹²	No – included within group of minorities	Retrospective review of outcomes with a home-based palliative care program offered at Kokua Kalihi Valley	Kalihi, in urban Honolulu on O'ahu in the state of Hawai'i	Found an increased AD completion rate (90%) and hospice enrollment for eligible patients (85%) in a group of patients in which all except one were a minority.
Anngela-Cole, et al, 2010 ¹³	Yes	Qualitative, focus groups of Hawai'i residents	Hawai'i	Emphasized the importance of understanding how historical trauma and cultural beliefs regarding death impact patients' and families in palliative care situations.
Kataoka-Yahiro, et al, 2016 ¹⁵	No – included within Asians and native Hawaiians	Quantitative survey and qualitative interviews	2 nursing homes in Hawai'i	Found a need to improve culturally appropriate approaches and communication for palliative and EOL care services in these ethnic groups
Flavin, 1997 ¹⁶	Yes	Cross-cultural training program outcomes	Maui in the state of Hawai'i	The results of the program were statistically insignificant based on learning measures, however the program helped increase the staff's skills at interacting with the cultures based on participant comments.
Braun, et al, 2001 ¹⁴	No – included within Pacific Islanders (Hawaiian and Samoan)	Focus groups with Christian church members and clergy in Honolulu	Honolulu, on O'ahu in the state of Hawai'i	Church can have a major role in EOL care by helping congregants and their families prepare for death.

insignificant based on learning measures, the program helped increase the staff's skills at interacting with the cultures and highlighted an instrument that may be used to provide nursing education about cultural values.

Braun, et al,¹⁴ held focus groups with Christian church members and clergy in Honolulu to discuss death and dying. Twenty three percent of the sample identified as Pacific Islander. They concluded the church can have a major role in EOL care by helping congregants and their families prepare for death in ways such as preparing spiritually and practically, helping with conflict and forgiveness, providing comfort to ill members and their families, and clarifying how church theology may guide decisions related to death and dying.

Discussion

Limited data regarding usage of EOL care specifically in Native Hawaiians exists as the majority of articles group Native Hawaiians within larger categories such as Pacific Islanders, AAPI or Asian/Pacific Islanders. According to the 2010 US Census, Native Hawaiians comprised 43% of the 1.2 million of the total Native Hawaiian and Pacific Islander (NHPI) population. A projected 2.6 million Americans will identify themselves as NHPI by 2050.¹⁸ The paucity of the data regarding the use of EOL care in the growing population of Native Hawaiians

makes it evident more research needs to be conducted on Native Hawaiians specifically so as not to miss possible disparities which may be masked by the larger NHPI category.

With the aging population and increasing cost of healthcare, EOL care discussions are imperative for improving the quality of life for patients and creating a sustainable healthcare system with significant cost-savings.¹⁹⁻²¹ Additional research in this topic will fill in the gaps of knowledge and provide the information necessary to support the development of culturally appropriate tools and clinical guidelines to initiate and facilitate the process of advanced care planning with Native Hawaiian patients and families.

The importance of EOL care discussions in the medical setting can be introduced in the medical education system.^{22,23} Training future physicians early in their careers about beliefs of different cultures and how to facilitate culturally-sensitive EOL care discussions in clinical practice may lead to increased comfort and less hesitation in holding these types of conversations with patients. Increased cultural competence has also been shown to be associated with positive health outcomes.^{24,25} Furthermore, the continued promotion of developing a Native Hawaiian health care workforce will potentially increase the number of Native Hawaiians delivering health care to Native Hawaiians. In addition, providers who are more familiar with Native Ha-

waiian culture and values could contribute by sharing effective strategies with their colleagues about how to have EOL care discussions with Native Hawaiian patients.

This is the first literature review specifically on Native Hawaiians and EOL care usage. Limitations to this literature review include the low number of relevant research articles. The conclusions drawn from the available articles may not be reflective of the current state of affairs regarding EOL care especially as the majority of the articles were published over ten years ago. Future research on the topic is imperative.

Conclusion

EOL care discussions are an important component of clinical practice and are especially relevant when considering the rapid increase in the seniors in the population. In the setting of an increasing Native Hawaiian and NHPI population, the paucity of research in the topic surrounding EOL care and Native Hawaiians is concerning and needs to be addressed in order to develop culturally appropriate tools and guidelines to assist in what can be difficult conversations for families and patients to have.

Conflict of Interest

None of the Authors identify a conflict of interest.

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