

Culture, Social Determinants of Health, and Palliative Care in the Pacific Basin

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Ua gatasi le futia ma le umele.

As the fisherman swings the rod, the others must assist by paddling hard.

—Traditional Samoan wisdom

Key Concepts

- *Collectivist-oriented values and interdependent relations* are key considerations in healthcare services delivered to people originating from the United States Affiliated Pacific Islands (USAPI), which includes three United States territories (American Samoa, Guam, Commonwealth of the Northern Mariana Islands), as well as the Republics of the Marshall Islands, Palau, and the Federated States of Micronesia.^{1,2} Collectivist cultures are characterized by attention to group needs, a cooperative work ethic, and a preference for cohesive, harmonious relations. Interdependence is typified by respect for individual needs and actions supported by mutual reliance.¹
- *Distal and detrimental social determinants of health (SDOHs)* influence the range of healthcare services available in the USAPI,^{1,2} and there are limited or no hospice and palliative care services at end of life (EOL).^{3,4} Thus, people from the USAPI being treated in the United States may be unfamiliar with these services and benefit from anticipatory guidance on what palliative and EOL services in the United States involve, with providers' close attention to issues of cultural health and death literacies.
- *Cultural health literacy (CHL) and death literacy (DL)*^{5,7} are recognized as essential in cross-cultural health transactions. Western healthcare culture evolves continuously in its medico-legal terminology, medical procedures, and technologies, which may cause confusion and misunderstanding among service users.^{1,5,6} Indicated is the need for CHL or organizational and interprofessional efforts that bridge cultural differences and minimize potential miscommunications.^{7,8}
- *Death literacy* is a significant offshoot of CHL and refers to knowledge and skills essential for acting upon EOL and death care options.⁷ Death literacy includes the understanding that dying at home is a common desire.⁸ Reasons may include the wish to resolve unfinished business, affirm significant relationships, bid a final goodbye to loved ones, and/or be in a culturally familiar environment.
- Generally, people from USAPI view their ancestral land as a living relation.¹ Returning to the homeland may connote connection with the place of one's ancestors and living relatives—both of which are essential to affirming Indigenous identity and completing the arc of one's life. It is important to attend to the wishes for returning

home before a patient becomes so ill that they are unable to travel. Many families, even with help from extended family, cannot afford to ship a body home and this meaningful aspect of EOL ritual becomes unattainable for some and may precipitate crisis.

- *Social workers in palliative and EOL care often serve as cultural mediators and/or process facilitators,*^{4,9} who are called upon to address extenuating circumstances. As cultural mediators, they broker and triage diverse cultural perspectives and act as a communication conduit between service providers and users. As process facilitators, palliative social workers (PSWs) enable positive outcomes in potentially contentious discussions and leverage culturally relevant solutions.

Introduction

Samoan wisdom uplifts collectivist-oriented values and interdependent relations to an imperative. The fisherman is the key actor but relies on others to achieve the desired outcome. This wisdom also is applicable to other collectivist-oriented Pacific Islanders and to the interprofessional palliative team (IPPT). The IPPT's core competency is to lead from each professional's expertise while in close collaboration. Such collaboration is demonstrated in the narrative of Mareta (see Box 51.1), a Samoan national living in the United States and treated for advanced cervical cancer, with metastasis to the lungs. Mareta's dying wish is to return to American Samoa. The IPPT deems travel a medical risk, questions her decisional capacity, and orders a psychiatric evaluation. Mareta threatens discharge against medical

Box 51.1

Patient Narrative—Mareta “I just want to go home . . . now!”

Mareta is a 39-year-old female of Samoan ethnicity from the Territory of American Samoa and is a US national. Due to limited employment and educational opportunities, the family relocated to a US state about 2 years prior to Mareta's hospitalization. Immediate family members include loane, her husband, and their adolescent children, losefa and Sina. Mareta works within the home and is active with the local Samoan church. loane secures employment as a sous chef in a unionized hotel. His benefits include medical coverage for the entire family. The children, reportedly, are making good academic and social progress, active with their church youth group, and support the household through routine *fe'au* (chores). Contact with her American Samoa-dwelling family is maintained through weekly voice or video calls.

About 1 year after relocation, Mareta complains of chest pain and breathing difficulties; she is taken to the local hospital. Examinations and tests yield a diagnosis of cervical cancer, stage IVB with metastasis to the lungs. No standard treatment is available. She is given a 1-year prognosis. Due to the family's work and school schedules, she is hospitalized for respiratory difficulties that could not be managed in the home. Mareta consistently states to the inpatient palliative care team (IPPT): “I just want to go home . . . now!” She explains the importance of spending time with family in the ancestral home. However, doctors strongly discourage air travel as it poses a significant medical risk. A crisis ensues. Mareta threatens discharge against medical advice. The IPPT physician speculates that she has limited decisional capacity. A psychiatric evaluation is ordered. When loane learns of the referral, he strenuously objects: “This is the last straw. My wife is not crazy. She just wants to go home. Can't you give a dying person their last wish?” The psychiatric consult is cancelled when the PSW mediates by explaining the cultural meaning of homeland to the interprofessional team caring for Mareta.

The PSW meets daily with Mareta, who is encouraged to speak about her needs, beliefs, customs, and homeland. Mareta's concerns focus primarily on her children and her desire to return to her homeland. With parental consent the PSW arranges a meeting with Mareta's children. Specifically addressed are children's questions on mother's medications and prognosis. In collaboration with Mareta and loane, the PSW works collaterally with the school social worker, who agrees to periodically check in with losefa and Sina. The PSW realizes the importance of Mareta seeing her American Samoa-dwelling family and contacts the American Samoa Community Cancer Coalition for advice. A video conference is arranged. Mareta sees and speaks with her American Samoa relations. *Faife'au* (ministers) from Mareta's churches in American Samoa and the United States offer prayer, homily, and blessings. The family sings *pese lotu* (hymns) and performs *siva* (traditional dance). Mareta dies 1 week later in the hospital. loane, losefa, and Sina take her body back to American Samoa. Mareta's life is celebrated with *fa'alavelave* (customary rituals for the passing of a loved one). She is laid to rest in her ancestral village.

advice. Her husband protests: "Why can't you give a dying person her last wish?!" The palliative social worker seeks a solution which honors adherence to care and Mareta's dying wish.

Background: American Samoa and the US Pacific Basin

The 2010 US Census reports the growth of the Native Hawaiian and Other Pacific Islander (NHOPI) population in every US state, with Samoans as the second most numerous Pacific Islander population living in the United States.¹⁰ Our chapter highlights key issues in palliative and EOL social work practice with Samoans from the culture-rich, yet resource-constrained Territory of American Samoa.

Collectivism, Interdependent Relations, and Perpetuation of *Fa'asamoa*

Indigenous Samoans are the oceanic people who settled the Samoan Archipelago nearly 3,000 years ago.¹ Prior to European and American contact, an Indigenous governance system known as *fa'amatai* (way of the chiefs) was organized. This system was ensured through practice of *fa'asamoa* (Samoan ways) or lifeways rich in collectivist values and interdependent relations. *Alaga'upu* (ancestral wisdoms) stress responsibility to share in the work deemed essential for the well-being of all and continue to be referenced in contemporary times. Traditional culture, language, governance, and a village-based land tenure system are purposefully preserved. According to the American Samoa government, an estimated 91% of the ethnic Samoan population use *le gagana fa'ai'u* (the mother tongue) at home and in other situations requiring contextual meanings not adequately expressed in English.¹ While culture-rich, American Samoa is beset by extensive health and social disadvantage, with no/low hospice or palliative care facilities.^{1,4}

Social Determinants of Health

American Samoa is resource constrained, it is challenged by multiple political and socioeconomic factors. Taken together, these factors affect healthcare services and population health; arguably, territorial status itself is a de facto SDOH.¹

Political Factors

American Samoa is one of five unincorporated US territories; by definition, the US Constitution only partially applies. The territories are subject to US plenary power (complete, absolute authority), federal laws, and treaties. Under US constitutional law, territorial residents are without suffrage in US presidential elections, and their representatives to the US Congress have no vote. Thus, residents of American Samoa and the four other territories are hindered in their capacity to influence policies that may directly affect their health and well-being. However, unlike residents of the other US territories, those born in American Samoa are at birth designated as US nationals (may live in US states but without all rights of citizenship).

Socioeconomic Factors

As a US territory, American Samoa is not able to negotiate its own treaty agreements (e.g., commercial fishing) and is subject to US federal laws (e.g., US minimum wage laws). Thus, US policies, generally, have not always benefitted American Samoa and have resulted in the territory's low gross domestic product and relatively high poverty levels. Poverty is the most robust and detrimental SDOH, with ill health presenting a cascade of barriers.¹ The 2010 US Census indicates that the US overall poverty rate by household income, with geographic adjustment, is about 14.8%. By comparison, the American Samoa adjusted poverty rate is 57.8%, a rate higher than that of all US states, the District of Columbia, and all other US territories.^{1,10} Because such a high percentage of the population lives at or below the US federal poverty level, Medicaid funds are directed to the territory's sole hospital. American Samoa is expected to contribute a nonfederal share to access Medicare and Medicaid funds. This has been a challenge to a territorial economy with a negative trade balance and struggling to survive.¹ Given these circumstances, provision of palliative and hospice care, while needed, is severely limited.^{3,4} There is one acute care facility in American Samoa: the LBJ Tropical Medical Center, which provides palliative medical care.^{1,3,4} A recent American Samoa report⁴ indicates that health social workers are involved in palliative care and specifically responsible for ensuring culturally relevant, linguistically appropriate communications between patients, families, and providers. Upon discharge from the medical care center, families are responsible for administering medications, with oversight from public health nurses when indicated. There is a church-supported nursing facility which offers elders and persons with physical disabilities

assistance in bathing, getting dressed, and other activities of daily living.^{3,4} There is no hospice program, and families are responsible for care of their dying relative.⁴ Thus, patients originating from American Samoa may be unfamiliar with hospice and palliative care as provided in the US states. We present the narrative of Mareta, a Samoan national receiving care in a US state (see Box 51.1).

Conclusion

Our chapter describes the need for cultural health and death literacies in a palliative, EOL setting. The patient and her family members were unfamiliar with Westernized palliative care, and the team was unfamiliar with Samoan cultural values held by the family. This fueled misunderstanding. From social work's ecological perspective, we underscore the ways in which SDOH influence cancer prevention and control in populations of comparatively small numbers and in dispersed, relatively isolated geographic areas like the USAPI.¹⁻³ In the US states, cervical cancer is preventable through screening tests and vaccination to prevent human papillomavirus infections.² When found early, cervical cancer is treatable, with promising survival outcomes. Unfortunately, such benefits are not enjoyed by USAPI-dwelling women who suffer disproportionately from cervical cancer stemming from the dynamic interaction of political systems, health system (under)funding, and other aspects unique to American Samoa and the other USAPI territories and nations.^{2,3} It is crucial for health and palliative social workers to think globally and act collaboratively with professional and advocacy organizations. As we peruse the chapters in this textbook, we are reminded of the urgent, yet daunting challenge to advance health equity for all. We close our chapter in the way it was begun with a Samoan *alagaupu* (traditional elder wisdom)—one which reminds us that the strength to keep moving forward comes from working together for and with others:

O le tele o sulu e maua ai se fagota, e mama se avega pe a ta amo fa'atasi.

My strength does not come from me alone, but from many.

Learning Exercises

1. How are your beliefs and practices like those of Mareta? How would you ensure sensitivity in the assessment of meaning and culturally safe practice

with those whose values and circumstances differ from yours?

2. How do distal SDOHs influence the couple's choice to relocate to a US state? How do they influence the couple's understanding of palliative care services?
3. Health literacy is intended to minimize confusion of service consumers and their communications with culturally diverse providers. Discuss how you might apply cultural and health literacy strategies from the National Roundtable on Health Literacy,⁶ including training on communication strategies and tailoring health information for cultural health and death literacy.

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